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**Black African service users' experiences of recovery from mental illness in  
England**

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**Thesis submitted for the degree of PhD in Mental Health Nursing, School of Health  
Sciences, City University London**

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## ABSTRACT

**Background:** Recovery is a complex and contested concept. Many studies have explored the meaning of the concept from the perspectives of service users suffering from mental illness. However, too little attention has been paid to the experiences of Black African service users (BASUs) living in England. At the time of writing this work there were no studies that have explored recovery from the perspectives of BASUs in England.

**Aims of the study:** The aim of the present study is to explore experiences of recovery from mental illness of BASUs in England.

**Methodology and methods:** Semi-structured interviews were conducted with twelve BASUs. The interviews were analysed using Interpretative Phenomenological Analysis (IPA).

**Findings:** Five superordinate themes were derived from the analysis: (1) it is different in Africa; (2) it all started in England; (3) shattered; 4) 'freaked out'; and (5) focus on recovery. An in-depth explanation of these superordinate themes and the related subordinate themes is presented. The findings highlight the multifaceted ways in which BASUs understand their experiences of mental illness and recovery.

**Discussion:** The insight gained from these findings provided rich information about the complexities of the participants' experiences of recovery from mental illness. Participants' explanatory models of mental illness included the complexities of migration, African-centred worldviews and negative life experiences. Participants conceptualised recovery in the context of their social and cultural backgrounds, remission or eradication of symptoms, spirituality, resourcefulness, resilience and unique personal identities. An emerging conceptual model of recovery is formed (Figure 3).

Findings are discussed considering existing theory and literature. Implications for clinical practice in relation to the provision of care and promoting recovery for BASUs in England are considered.

## PROLOGUE

The expressions Black, Black African and Sub-Saharan Africa, as well as mental illness, mental disorders and mental health problems, which are all used within this study, are often recognised for their complexity and thus require both explanation and qualification.

For the purposes of this thesis, the term 'Black' refers to a person with African ancestral origins; however, there is recognition that the term potentially conceals significant heterogeneous cultures of the diverse African populations and it risks reinforcing racial stereotypes (Agyemang, Bhopal and Bruijnzeels, 2005). Furthermore, the term Black is potentially offensive and unreliable (Senior and Bhopal, 1994) because Black people, just as with other ethnicities, may have mixed heritage and may or may not wish to identify themselves as Black or British (Office of National Statistics, 2012). Others may identify themselves as Black, but may not have a sense of belonging to a place or heritage (Gardener and Connolly, 2005; Atkinson et al., 2008). In the UK, the term has political connotations and it is frequently used to describe a shared experience for those who have experienced colonial or racist oppression by British colonialism (Afridi and Warmington, 2009). The term is also used by Asians who believe that their common experience of racism outweighs cultural differences (Institute of Race Relations, 2014; Lingayah, 2011). It is important to point out that substantial heterogeneity exists across Black people in the UK with regards to culture and colonial history. African and African Caribbean people in the UK have different experiences of migration, socio-economic trajectories and cultural and family settings (Lingayah, 2011). For example, language, culture and allegiances vary among the peoples of the Caribbean islands and an individual may prefer to identify with the island he or she originates from, rather than

the stereotypical Black or Caribbean identity imposed in the UK (Fryer, 2010).

Black African is a term generally used to refer to people and their descendants with African ancestral origins who have migrated from Sub-Saharan Africa. However, the terminology has been subjected to contentious debate due to substantial diversity throughout African countries, and continuous collective use of the Black African term could therefore be called into question (Aspinall and Chinouya, 2008). For example, some Somali people in England identify themselves with Arab cultures and have challenged being classified as Black Africans (Agyemang, Bhopal and Bruijnzeels, 2005). Here the term Black African is used to refer to any immigrant or second-generation immigrant who identifies as Black African. Therefore, an individual's 'self-concept' or perception of identity is crucial, because they are formed by their experiences and interpretations of their world domain (Rosenberg, 1979). Arguably, the second-generation Black Africans are not a generation of migrants, but they are likely to have similar experiences of cultural identity, stress, stigma and discrimination associated with first-generation Black Africans (Bhugra and Jones, 2010). Strengthening this point is the study by Dustmann, Frattini and Theodoropoulos (2010) who found that the second-generation ethnic minority immigrants are better educated than their first-generation counterparts and their white British born peers, but compared to their white British born peers with similar qualities, second-generation ethnic minority immigrants are likely to be underemployed and earn on average lower wages.

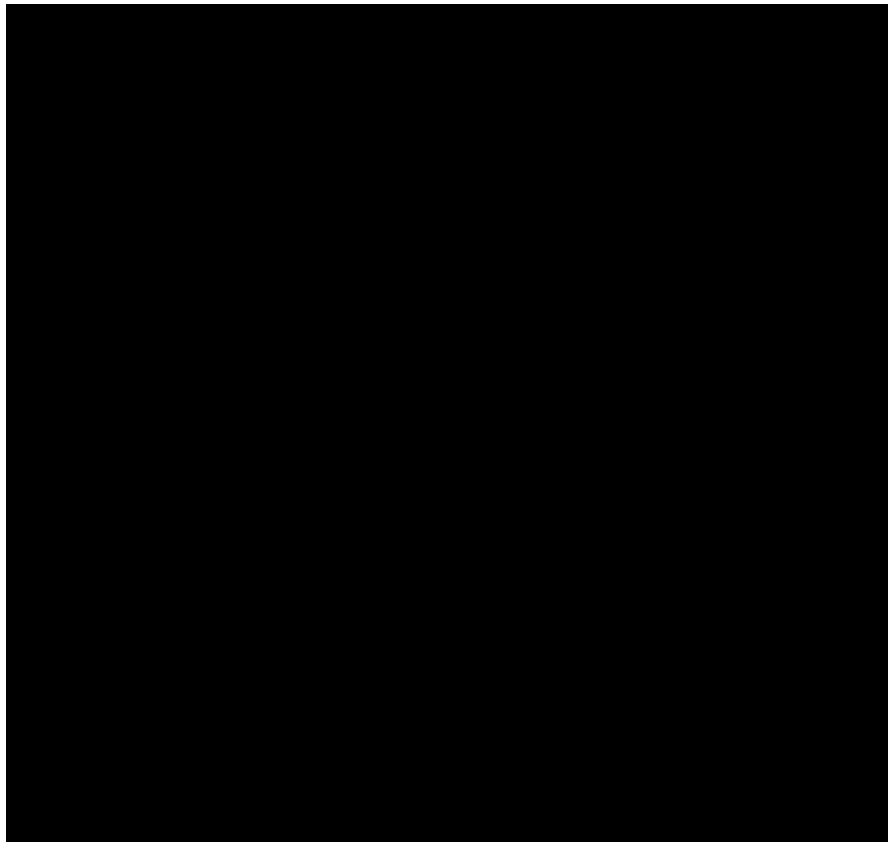
In using the term 'Black African' I acknowledge the diversity within Sub-Saharan Africa and the Black African population in England. By referring to 'Africa' or 'Black African' I do not suggest that there are no differences between people from the various countries within the

continent. Of course, Black Africa is extremely diverse, with various cultures, languages and nations. However, throughout this thesis, I use the terms 'Africa', 'African', 'Black African' and 'Sub-Saharan Africa' to essentially illustrate that there are some shared views common to all the participants of this thesis.

Sub-Saharan Africa is defined as the region of Africa south of the Sahara Desert (see map below); the term has geographical and political connotations. Geographically, countries like Sudan, Somalia, Djibouti, Comoros and Mauritania are all part of Sub-Saharan Africa (United Nations, 2013), however, these countries align themselves politically with the Arab world (Arab League Online, 2012).



**Figure 1: A political map showing the boundaries of African countries (Sub-Saharan Africa in white)**



**Source:** Google – Sub-Saharan Africa Map Quiz

Similarly, certain quarters do not generally consider Mauritius as a Sub-Saharan African island nation as the ethnic make-up of the country is predominantly East Indian, Chinese and French. Yet despite this, it is always counted as one of the Sub-Saharan African countries (Ondari-Okema, 2007). This implies that some individuals from these countries and cultures may not necessarily consider themselves as Sub-Saharan Africans or Black Africans, something that this thesis makes space for. This study focuses on persons who identify themselves as belonging to the geographical region of Sub-Saharan Africa or Black Africa.

The World Health Organization (WHO) (2014) defines mental health as: ‘a state of well-being in which an individual realizes his or her own abilities, can cope with the normal stresses of life, can work productively and is able to contribute to his or her community’. Mental health in this context is clearly something positive. Thus, a person is deemed to have mental disorders, mental health problems or a mental illness if he or she is not able to realise his or her abilities, cannot cope with normal stresses of life and cannot work productively to contribute to his or her community.

The terms ‘mental illness’, ‘mental disorders’ and ‘mental health problems’ are generally used interchangeably or synonymously in mental health literature. For the purposes of this thesis, the following definition will be adopted:

‘A mental disorder is a syndrome characterized by clinically significant disturbance in an individual's cognition, emotion regulation or behaviour that reflects a dysfunction in the psychological, biological, or developmental processes underlying mental functioning. Mental disorders are usually associated with significant distress in social, occupational, or other important activities. An expectable or culturally approved response to a common stressor or loss, such as the death of a loved one, is not a mental disorder. Socially deviant behaviour (e.g., political, religious or sexual) and conflicts that are primarily between the individual and society are not mental disorders unless the deviance or conflict results from a dysfunction in the individual, as described above.’ (American Psychiatric Association, 2012)

The definition above is broad, inclusive and reduces labelling. It also encompasses the medical, functional and socially defined perspectives. However, the underlying assumptions of the terms ‘mental illness’ and ‘mental disorders’ place emphasis on a medical model and reduce individuals to a ‘sick role’ (Parsons, 1951). Despite this, for the purposes of this thesis the term ‘mental illness’ is preferred due to its collective meaning. According to Kleinman (1980), ‘illness’ does not only affect an individual, but also the family, the social network and

sometimes the entire community in some cultures. Given that most African cultures are said to be communalist (Gyekye, 1997; Mbiti, 1990; Menkiti, 1984; Scheile, 2015; Wiredu, 1996), it is reasonable to adopt such terminology.

Table 1 provides additional definitions of terminologies used in this thesis.

**Table 1: Glossary**

BASU	Black African Service User
Black and Minority Ethnic (BME) Groups	In the UK, the BME terminology is normally used to describe people of non-white descent (Institute of Race Relations, 2014). Some critics point out the term's emphasis on skin colour and prefer the non-colour term 'minority ethnic', while others prefer an inclusive term 'Black, Asian and Minority Ethnic' (BAME) (Afridi and Warmington, 2009). While a variety of definitions have been suggested, the term 'Black and Minority Ethnic' (BME) is preferred, recognising that this was the term employed by the Department of Health (2005a) in <i>Delivering Race Equality in Mental Healthcare</i> .
Consumer	The term 'consumer' is used as a general description of the people who use mental health services.
Culture	For the purposes of this thesis, a psycho-behavioural definition of culture by Marsella and Yamada (2000, p.12) is adopted: 'Shared learned meanings and behaviours that are transmitted from within a social activity context for purposes of promoting individual/societal adjustment, growth, and development. Culture has both external (i.e., artefacts, roles, activity contexts, institutions) and internal (i.e. values, beliefs, attitudes, activity contexts, pattern of consciousness, personality styles, epistemology) representations. The shared meanings and behaviours are subject to continuous change and mediation in response to changing internal and external circumstances'.
Ethnicity/Ethnic Group	Rather than race, which is believed to have negative connotations, ethnicity or ethnic group is often preferred in

acknowledgment of the fact that different races may share a similar culture (MacLachlan, 2006). Ethnicity encapsulates a range of attributes used to identify a group of people whose members identify with each other through a common heritage, often consisting of a common language, culture, religion, ideology and ancestry (Institute of Race Relations, 2014). However, ethnicity is a multi-faceted concept that can be approached in different ways, for example, the commonalities within a group or differences from 'other' groups (Burton, Nandi and Platt, 2008).

LREC	Local Research Ethics Committee, which forms part of the National Research Ethics Service for the NHS (NRES).
NHS	National Health Service
Race	The term race is often characterised by the physical appearance of a person (Institute of Race Relations, 2014). The term has three usages: biological, common and political (Fuller and Toon, 1988). It is used biologically to refer to the genetic differences in 'racial' groups. However, the boundaries between races are arbitrary. Considering that there is a wide genetic difference within each race, the differences between two individuals within the same racial group may be on average greater than between two different racial groups. In common usage, race is synonymously used to refer to physical appearance and skin colour. Politically, the term is used by majority groups to consolidate power and by minority groups to politicise their identity (Bhugra and Ayonrinde, 2001).
Service User	The term 'service user' is used as a general description of the people who use mental health services.

## **CHAPTER ONE: INTRODUCTION AND BACKGROUND**

### **1.0 Introduction**

The aim of this thesis is to contribute to the understanding of recovery from the perspectives of Black African service users living in England. Most participants in this study have immigrated to England escaping political disorder, wars, persecution and poverty and have come from countries that were previously subjected to British colonialism. Others moved due to economic factors and poor governance in their country. Post-migration stress of adaptations, marginalisation and disconnection from social networks (Herman, Kaplan and Szwarc, 2010) led to feelings of isolation, confusion and a sense of helplessness, which triggered or exacerbated an existing mental illness.

An in-depth exploration of experiences of recovery of 12 Black African people living in England and experiencing mental illness has been undertaken using Interpretative Phenomenological Analysis (IPA). IPA is a methodology designed to both examine and interpret how people make sense of their major life experiences (Smith, Flower and Larkin, 2009). This chapter provides the background and context for the thesis. The chapter begins by presenting the background and rationale of the research, it is then followed by a presentation of the research question, aims and objectives and the chapter concludes with an outline of the organisation of the thesis.

### **1.2 Background and rationale**

Broadly speaking, the literature on mental health recovery describes it as a complex and idiosyncratic process that is difficult to conceptualise (Davidson et al., 2005; Liberman and

Kopelowicz, 2005; Onken et al., 2007; Roe, Rudnick and Gill, 2007). Perkins and Slade (2012) have suggested that there is no 'blueprint' for recovery largely due to the individual nature of the recovery journey. Yet despite its intrinsic individualised meaning, recovery has been adopted and operationalised by many national mental health service providers (Slade, Amering and Oades, 2008). However, in a recent cross-national study in England and Wales, Simpson et al. (2016) found wide discrepancies between recovery policy and practice and the authors concluded that the ideals of recovery-oriented approaches have been dampened by the mental health services. They particularly lamented that the ambitions for recovery to provide culturally sensitive mental health care continues to remain elusive.

Despite this, there is increased recognition about the importance of giving a voice to and developing an equal partnership with service users (Shepherd, Boardman and Slade, 2014). Consequently, individuals in many developed countries who are personally affected by mental illness have become increasingly involved in how recovery should be conceptualised (Slade, Adams and O'Hagan, 2012). However, far too little attention has been paid to the voices of Black Africans living in England and experiencing mental illness. In fact, there appears to be no research to date that has specifically asked people from Sub-Saharan Africa living in England about their experiences of recovery from mental illness.

Findings from the literature search revealed a large volume of published studies on topics about resources for recovery including: personal meanings of recovery (Le Boutillier et al., 2011; McEvoy et al., 2012; Piat et al., 2009); hope (Hobbs and Baker, 2012; Perry, Taylor and Shaw, 2007; Waynor et al., 2012); choice, self-control and empowerment (Jensen and Wadkins, 2007; Mancini, 2007); spirituality (Bussema and Bussema, 2007; Russinova and

Cash, 2007); and personal and social relationships (Davidson et al., 2005; Schön, Denhov and Topor, 2009; Borg and Davidson, 2008). Insights from these studies revealed that there is a potential for everyone with mental illness to recover. However, most of these studies discussed recovery from Western perspectives (Adeponle, Whitley and Kirmayer, 2012) with markedly little or no attention paid to the Black African service users' perspectives.

It is important to mention that the small number of studies that have been conducted from the perspectives of BME service users help to provide insights into the experiences of a small number of ethnic minorities. These include: Kalathil (2011) in England; Lapsley, Waimarie and Black (2002) in New Zealand; Armour, Bradshaw and Roseborough (2009) in the USA; and Jacobson and Farah (2012) in Canada. However, a closer look at some of these studies shows that some authors grouped and discussed experiences together regardless of racial and cultural backgrounds; therefore many of these studies fail to make a summative evaluation of BASUs' experiences.

There are currently very few empirical studies of recovery undertaken from the perspectives of BASUs. Those that do exist include: Gandi and Wai (2010); de Wet, Swartz and Chiliza (2015); Kleintjes, Lund and Swartz (2013); and Kleintjes et al. (2012). However, all these studies were conducted in Sub-Saharan Africa and not in England. Moreover, some of these studies did not explicitly seek to explore the lived experiences of the participants.

Available evidence suggests that there is a cultural context for concepts of mental illness in many African cultures. Studies conducted in many Sub-Saharan African countries revealed that witchcraft, supernatural powers, spirit possession and angered ancestors are often cited

as the causes of mental illness (Abbo et al., 2008; Muga and Jenkins, 2008; Mzimkulu and Simbayi, 2006; Olugbile, Zachariah and Isichei, 2007; Patel, 1995; Ventevogel et al., 2013).

Whilst these studies add substantially to our understanding of the exploratory models of mental illness of service users in Africa, there is a lack of detailed phenomenological accounts eliciting the meanings of mental illness and perceptions of recovery of BASUs in England. These research gaps have necessitated this IPA research study. Below, I present the research question and objectives.

### **1.3 Research question**

What are the lived experiences of Black African service users (BASUs) in England recovering from mental illness?

### **1.4 Research Aim**

The aim of the present study is to explore the experiences of recovery of BASUs in England in relation to their mental illness.

### **1.5 Research objectives**

- To explore the explanatory models BASUs provide for their mental illnesses.
- To explore BASUs' experiences with the mental health services in England.
- To explore the key factors that promote the recovery of BASUs.
- To explore the meanings BASUs assign to recovery.

### **1.6 Overview of the Thesis**

This thesis has been organised as follows:



Chapter Two critically explores the various ways recovery has been conceptualised in mental health and intellectual disability services. Conceptualisations of resilience are also explored.

Chapter Three presents a literature review of empirical studies on recovery.

Chapter Four discusses the theoretical frameworks for addressing the aims of the research. It discusses the rationale for a qualitative, phenomenological approach employing the theoretical underpinnings of IPA.

Chapter Five discusses the methods used in the study. The study's design is discussed in detail, including sampling procedure, ethical issues and the process of data collection and analysis. The critical assessment of the quality and rigour of the research process are also discussed.

Chapter Six presents the findings of the study. The main themes emerging from the data analysis are broadly discussed in this chapter. Excerpts from the participants' narratives, along with my own analysis, are used to highlight and illustrate themes.

Chapter Seven provides a synthesis of the findings and the conclusion of the study, including my theoretical and methodological contribution to knowledge. Strengths and weaknesses of the study are provided, as well as recommendations for future research.

Chapter Eight is devoted to my reflections on the research process.

## **CHAPTER TWO: CONCEPTUALISATIONS OF RECOVERY AND RESILIENCE**

### **2.0 Introduction**

One of the main challenges facing service users, professionals, researchers and policy makers is the wide-ranging ways in which recovery is understood and conceptualised. Attempting to identify a concise definition of recovery is not a simple task. The scholarly literature is scattered, with conceptualisations dotted around disciplines such as physical disability, addiction services, intellectual disability services and the various specialties of mental health services. Furthermore, the many contexts and disciplines in which the term recovery is used include archaeology, conflict politics, economics, arts and culture, sport and even transport, with regard to recovery vehicles (McCauley et al., 2015). This further complicates the concept. The aim of this chapter is to explore some of the multifaceted ways in which recovery has been conceptualised in mental health and intellectual disability literature. The chapter begins with the challenges of conceptualising recovery; this is then followed by scientific definitions of recovery and then consumer-oriented definitions. The conceptualisation of recovery as a social process is discussed next, followed by a discussion of recovery using a dimensional approach. The concept of recovery in the intellectual disability services is discussed, followed by a brief discussion of the social model approach and then conceptualisations of resilience.

### **2.1 The Challenge of Conceptualising Recovery**

The mental health recovery literature suggests that the concept of recovery is difficult to conceptualise (Davidson et al., 2005; Liberman and Kopelowicz, 2005; Onken et al., 2007; Roe, Rudnick and Gill, 2007; Simpson et al., 2016). There is a consensus that recovery has different meanings to different stakeholders (Kelly and Gamble, 2005; McCauley et al., 2015).

Discussions of recovery involve many terms, such as ‘an approach, a model, a philosophy, a paradigm, a movement, a vision and, skeptically a myth’ (Robert and Wolfson, 2004, p.38), and even a ‘buzz word’ or ‘fad’ (Piat and Lal, 2012, p.294). It has thus been criticised as an elusive and abstract concept (Davidson et al., 2005; Onken et al., 2007). Attempts to conceptualise a succinct construct of recovery are therefore doomed if they fail to recognise that it is a contested construct. Despite its illusory characteristics, however, there is a desire for its implementation by service providers to meet the needs of individual service users, consequently leading to more confusion about the concept.

McCauley et al. (2015) have highlighted many surrogate terms used in place of recovery by some influential individuals and several disciplines. For example, it has been conceptualised as ‘the birth of hope’ and ‘resurrection’ (Deegan, 1988, p.56-57) and ‘a journey of the human heart’ (Deegan, 1996, p.92). Likewise, the medical meaning has influenced the conceptualisation of recovery in psychiatric and mental health nursing, and behavioural sciences literature. Consequently, the terms ‘recovery’ and ‘rehabilitation’ are often used interchangeably (McCauley et al., 2015). Critics point out that the baffling use of interchangeable terminologies rooted in different philosophies is rarely made explicit (Collier, 2010; Davidson et al., 2005). It appears that attempts to conceptualise this complex and multifaceted concept have resulted in a terminological minefield. Reading through the extensive literature, I am convinced that a complete and succinct conceptualisation of recovery will always remain elusive. The literature does not offer an absolute definition. Instead, there are descriptions of quintessential qualities of recovery and there seems to be little, if any, agreement on what constitutes a pure definition of recovery. Despite this, it is

possible to identify many of the broad-spectrum definitions characterising the concept.

To begin with, some accounts illuminate dual conceptualisation: scientific- and consumer-oriented definitions (Bellack, 2006; Davidson and Roe, 2007; Slade, 2009; Silverstein and Bellack, 2008). Collier (2012, p.17) refers to these as the traditional and the contemporary definitions of recovery, or the 'medical' recovery and 'life' recovery. Others conceptualise recovery as either an outcome with operationally defined criteria, or as an ongoing process encompassing self-concept (Silverstein and Bellack, 2008). Some of these conceptualisations are further discussed in the following sections.

## **2.2 Scientific Definition of Recovery**

Broadly speaking, the literature considers scientific definitions of recovery from the perspective of disease and elimination or reduction of symptoms, return to premorbid state of function, use of medication, risk-management and acquisition of activities of daily living (e.g. Le Boutillier et al., 2015). The scientific definitions are known to have derived from the historical context of clinical research (Bellack, 2006; Davidson and Roe, 2007; Slade, 2009; Silverstein and Bellack, 2008). Thus, this is also referred to as clinical recovery (Slade, 2009). Adeponle et al. (2012) observe that one appeal of scientific definitions lies in their claim to offer a consistent measure of outcome irrespective of individuals' cultural backgrounds and geographical settings. However, a more fundamental objection to this argument is that significant variations exist in different cultural systems with regard to health and healing practices (Kirmayer, 2004). It can be argued that mental illness and recovery manifest differently to a native English service user and a BASU in England. In this sense, recovery cannot be defined by only scientific conceptualisations.

Operational scientific definitions of recovery include that of Torgalsbøen and Rund (2002), who use the following criteria: 'a reliable diagnosis of schizophrenia at an earlier time but not at present; no psychiatric hospitalizations for at least five years; and present psychosocial functioning within the 'normal' range on the Global Assessment of Functioning scale' (p.312). An alternative operational definition is provided by Harrow et al. (2005), who developed an explanation requiring a year's period of absence from psychotic and negative symptoms; adequate psychosocial functioning including paid work half-time or more; the absence of a very poor social activity level; and no rehospitalisation. Another scientific definition is provided by Liberman et al. (2002), who operationalise the concept with dual criteria of psychopathology and psychosocial functioning. The psychopathology criteria consider recovery as symptom remission and a score of '4' or less (suggesting moderate or less severity scores) on the Brief Psychiatric Rating Scale (Ventura et al., 1993). However, psychosocial functioning consists of vocational functioning with benchmarks such as: full- or part-time employment/education; involvement in recreational, family and volunteer activities; independent living without every day supervision by family or care providers; and relationships with significant others for regular social and recreational activities (Liberman et al., 2002). Finally, Liberman et al. (2002) conclude that each of the above criteria must be sustained for at least two consecutive years to satisfy the standards for recovery.

The definitions above highlight that recovery is not only about symptom remission, but is also marked by a multiplicity of important life activities, including work and social relationships. However, a notable limitation of these definitions is that they fail to address the subjective interpretation of the individual's level of functioning or the extent of the person's satisfaction

with life (Bellack, 2006). Specifically, they fail to incorporate the phenomenological and subjective experiences of the individuals experiencing mental illness. Moreover, as Bellack (2006) points out, scientific definitions have been determined by consensus and not empirically. Accordingly, there is no gold standard by which to define certain criteria such as quality of life or service user satisfaction (Silverstein and Bellack, 2008). Similarly, prominent service-user issues, such as the duration of recovery, acceptable residual symptom levels and acceptable functioning levels, have not been analysed to ascertain construct validity. Bellack (2006) also points out that the diverse perspectives of professionals, family members and consumers have not been systematically incorporated into the definitions. Finally, these conceptualisations must be interpreted with caution considering that the definitions are reflections of the narrow confines of schizophrenia. The key point to note is that these definitions are not inclusive considering that a wider spectrum of diagnoses is not considered in these conceptualisations.

### **2.3 The Consumer-oriented Definitions**

The consumer-oriented definitions are also conceptualised as personal recovery. They view recovery as a non-linear process in which the person with mental illness strives to overcome his/her difficulties over time. These definitions evolved from the service user movements, along with a change in attitudes about mental illness that was triggered by a combination of social and political factors. Essentially, the target audience for the consumer-oriented definitions includes service users, family members, politicians, policymakers and clinicians. It has been argued that the overarching aims of these definitions are to influence policies and service provisions, as well as to overcome the negative consequences, such as poverty,

stigma, demoralisation, hopelessness and social isolation, that are associated with mental illness (Bellack, 2006; Davidson and Roe, 2007; Slade, 2009; Silverstein and Bellack, 2008). Arguably, recovery in this context is conceptualised from the perspectives of reclamation of personal identity, dignity and social inclusion.

There is a plethora of consumer-oriented definitions of recovery, causing further confusion about the concept. One of the early definitions and perhaps the most widely accepted process-oriented definition of recovery is by Anthony (1993):

‘A deeply personal, unique process of changing one’s attitudes, values, feelings, goals, skills, and/or roles. It is a way of living a satisfying, hopeful, and contributing life even with limitations caused by the illness. Recovery involves the development of new meaning and purpose in one’s life as one grows beyond the catastrophic effects of mental illness’. (p.15)

Another widely cited process-oriented definition of recovery comes from Deegan (1988):

‘a process, a way of life, an attitude, and a way of approaching the day’s challenges. It is not a perfectly linear process’. (p.15)

Another good example of a process-oriented definition is by Davidson et al. (2005):

‘A redefinition of one’s illness as only one aspect of a multi-dimensional sense of self capable of identifying, choosing, and pursuing, personally meaningful goals and aspirations despite continuing to suffer the effects and side effects of mental illness’. (p.15)

More recently, a definition has emerged from a systematic review and narrative synthesis of staff understanding of recovery-orientated mental health practice:

‘a holistic approach (spanning physical health care, psychological therapies and stress management) where individuality (including client-centred goals, service-user autonomy and decision-making) takes precedence, and staff and service users work in partnership (through, for example, coaching, supporting hope). Personal recovery was measured by citizenship involvement (including

meaningful occupation and social inclusion)'. (Le Boutillier et al., 2015, p.6)

Almost all the definitions above appear to put emphasis on empowerment, control, choices and self-determination as having a profound positive effect on the individual with mental health problems (Andresen, Oades and Caputi, 2003; Bellack, 2006; Slade, Amering and Oades, 2008; Spaniol et al., 2002). They also appear to reject the scientific definitions of recovery (Andresen et al., 2003). However, what is surprising is that Anthony (1993) was inadvertently associating personal recovery with the scientific definition in his original construct when he suggested that service providers' vision of recovery from mental illness corresponds to 'cure or remission of symptoms' (Adeponle, Whitley and Kirmayer, 2012). This may not be surprising considering that some studies conclude that scientific or clinical definitions may exist in the minds of some service users (Davidson and Roe, 2007; Piat et al., 2009). Perhaps it is also not an exaggeration to suggest that these two definitions complement each other. As Silverstein and Bellack (2008) optimistically argue, neither of the opposing definitions is exclusively unique. The authors also make the analogy about recovery that construct validity is not merely attained by using the most reliable research measures, but by first addressing the meaningful dimensions of recovery before identifying and developing how to assess these dimensions.

Even with the optimistic perspective outlined above, it appears that there are numerous contradictions and complexities surrounding the conceptualisations of personal and scientific recovery. Crucially, all-important questions that need to be asked are: 1. 'Can there be a single definition of recovery that includes both process and outcome foci?' (Silverstein and Bellack, 2008, p.1110); 2. How do BASUs in England conceptualise their recovery from mental illness?



It remains to be revealed whether BASUs ascribe to clinical definitions, consumer-oriented definitions, a combination of both, or something altogether different.

## **2.4 Processes of Personal Recovery**

Some of the processes of consumer-oriented definitions include connectedness, hope and optimism about the future, identity, meaning in life and empowerment; these were given the acronym CHIME by Leamy et al. (2011) following a conceptual analysis of available international literature on personal recovery. Along with this comprehensive description, recovery has also been perceived as a process of hope, self-determination, agency, meaning/purpose and awareness/potentiality (Onken et al., 2007). Some have identified the recovery process as knowledge about mental illness and services, empowerment, hope and optimism and life satisfaction (Resnick, Rosenheck and Lehman, 2004), while others see the recovery process as finding hope, re-establishment of identity, finding meaning in life and taking responsibility (Andresen et al., 2003). These processes of recovery are not exhaustive by any means, but they are cohesive in their service user centeredness, and their focus on individuality, self-control and quality of life.

Despite the powerful focus on service users outlined above, Bellack (2006) argues that some of the consumer-oriented definitions are relatively non-specific, inadequate for research and ineffective for evaluation of clinical programmes or to develop public policy. Moreover, Silverstein and Bellack (2008) note that widely cited consumer-oriented definitions of recovery are characteristically generated by service users who have become experts by experience and thus their status within the professional community has propelled them to becoming mental health professionals. Silverstein and Bellack (2008) argue that it is unclear

whether the experiences of this cohort of experts are akin to the broader population of service users.

However, this criticism of consumer-oriented definitions may be a little harsh. The contemporary notion of recovery is in fact usually traced to the insights and writings of personal and transformative experiences of individual service users like Lovejoy (1984), Chamberlin (1997), Deegan (1988; 1996), Leete (1989) and Unzicker (1989) who have all articulated their experiences of coping with symptoms, getting their strength back, and regaining a satisfactory sense of personal identity that was not defined by illness experience. In addition, it is arguable that standardising and quantifying recovery would detract from the concept because establishing hierarchies of evidence in research (Aveyard, 2010; Greenhalgh, 2014) would mean that the anecdotal or personal accounts of the expert service users would be most likely excluded from the conceptualisations of recovery.

## **2.5 Recovery as an Ongoing Social Process**

A new perspective of recovery has emerged that proposes that some aspects of recovery unfold within a social and interpersonal context and therefore recovery cannot be solely focused on as a deeply personal and unique individual process. For example, it has been noted that having one or more personal relationships as a source of hope and encouragement can be a critical factor in achieving recovery (Spaniol et al., 2002). Mezzina et al. (2006) have produced a framework depicting personal, interpersonal and social domains, as well as the role of material resources and a sense of belonging as important sources of recovery. In this framework, the authors suggest that paying attention to issues relating to social inclusion, citizenship and participation in community activities are essential to recovery. Mezzina et al.

(2006) do, however, concede that the processes involved in their framework are complex and multidimensional as they require individuals to know about their conditions and to re-evaluate their purpose of existence in society. The authors point out that prior to reintegration into the social domain as valued citizens, individuals recovering from mental illness are expected to actively participate in these components mentioned above. However, Mezzina et al. (2006) tacitly recognise that social relations may be approached selectively and cautiously by certain individuals, possibly as a response to previous experiences of disappointment or rejection. An analogy can be drawn from this with some BASUs in England who may be victims of indirect and institutionalised discrimination (Department of Health, 2005a). Such negative experiences could reasonably lead to feelings of social rejection and isolation thus, some BASUs would be cautious or even reject social relationships as a facet of recovery. Some social aspects of recovery are equally unique individual processes like the personal recovery explicitly outlined above.

Topor et al. (2011) find in a qualitative study of 12 participants with diagnoses of severe mental illnesses that social relationships do not only play a central role in the recovery process, but they help individuals in recovery to feel that they are special. However, an analysis of contributory social factors to mental illness reveals antagonistic experiences of disempowerment, injustice, and abuse (Gilbert and Allen, 1998; Tew, 2011), often exacerbated by coercive and paternalistic service provision has adverse effects on relationships (Hughes, Hayward and Finlay, 2009). Tew et al. (2012) argue that an acceptable social environment is required to support service users to recover from incapacitating social situations and thereby recover from their mental illness.

## **2.6 Recovery as a Dimensional Approach**

Recent evidence also suggests that recovery can be conceptualised in a multi-dimensional approach. For example, following their review of the existing knowledge on recovery, Whitley and Drake (2010) proposed a compelling proposition that recovery can be conceptualised in five superordinate dimensions: clinical, existential, functional, social and physical. As with the scientific definitions described above, the authors suggest that clinical recovery involves reduction and control of symptoms. They support this view by explaining that this form of recovery is often intermediated by psychotropic medication and psychological interventions, and often spearheaded by the medical/care team. In this sense, the service users appear to lack control of their own recovery. Whitley and Drake (2010) further elucidate that the existential recovery may incorporate many components, such as religion and spirituality, agency and self-efficacy and empowerment, which often allows individuals with mental health problems to feel that they are in control of their own lives. The authors note that mental health services that take account of these existential needs of their service users are more likely to be effective. Interestingly, this form of conceptualisation appears to be consistent with some of the processes of personal recovery discussed above.

According to Whitley and Drake (2010), functional recovery includes factors such as employment, education and housing. Thus, functional recovery refers to the ability of the person with mental illness to fruitfully participate in all aspects of everyday human experiences. In this sense, functional recovery appears to have similar characteristics to consumer-oriented definitions of recovery, as it appears to put more emphasis on psychosocial functioning of the person with mental illness. Whitley and Drake (2010) suggest

that people with a serious mental illness may also experience multiplicity of comorbid physical health problems. Therefore, for these people, physical recovery is about continuous improvements in physical health and well-being. This form of recovery also appears to identify more with clinical recovery due to its emphasis on elimination or reduction of symptoms. Finally, Whitley and Drake (2010) explicate that social recovery involves establishing and maintaining meaningful relationships with family, friends, peers, clinicians and significant others, engaging in social activities, and being integrated into the community. This form of recovery appears to be consistent with the social process of recovery discussed above as it suggests that some aspects of recovery unfold within a social and interpersonal context.

As we have seen, the dimensional approach to conceptualisation of recovery provides a persuasive integrative approach to defining the concept. It appears to bring together the scientific-oriented definitions, consumer-oriented definitions and the social processes of recovery under one umbrella. In this regard, the centre of the dimensional approach to conceptualising recovery is consensus building; therefore, in the final analysis the power ought to be given to the service users to decide which of these dimensions are applicable to them. It remains to be discovered which of these dimensions BASUs would use to describe their recovery from mental illness.

Summarising the conceptualisations of recovery so far, the foregoing argument strengthens the idea that recovery is difficult to conceptualise. The concept has many facets and the challenge of conceptualisation is complex indeed. Interestingly, Adeponle et al. (2012) observe that the conceptualisations of recovery are dominated by Euro-American definitions and this has justifiably raised questions about the multi-ethnic relevance of the concept.

Arguably, understanding recovery from the perspectives of BASUs will serve as a framework for the exploration of recovery in minority cultures.

## **2.7 Concepts of Recovery in Intellectual Disability Services**

Based on the premise that the principles of recovery are less noticeable in intellectual disability services, Handley, Southwell and Steel (2012) rhetorically asked whether the principles of recovery are already being applied in intellectual disability services, but under a different name. They also questioned whether the concept is in fact applicable to people with intellectual disabilities and if so how it should be conceptualised.

As established above, some of the tenets of recovery are known to encompass social integration, choice and independence (Davidson et al., 2005; Hill et al., 2010; Repper and Perkins, 2003; Social Care Institute for Excellence, 2006); however, Handley et al. (2012) argue that these principles already existed in intellectual disability services before their adoption by the mainstream mental health services. For example, it is widely believed that some key theories pertaining to intellectual disabilities – the principles of normalisation, the set of ideals to ensure that people with disabilities have similar patterns of everyday living to everyone else (Wolfensberger, 1972), the social role valorisation or the theory for transacting human relationships and human service (Wolfensberger, 1983) place significant emphasis on community participation and social inclusion to enable people with intellectual disabilities lead fulfilled lives. Further, the introduction of policies such as ‘Valuing People’ (Department of Health, 2001), ‘Valuing People Now’ (Department of Health, 2009), ‘Putting People First’ (Department of Health, 2007), ‘Healthcare for All’ (Department of Health, 2008) and ‘A Life Like Any Other? Human Rights of Adults with Intellectual Disabilities’ (House of Lords, House

of Commons and Joint Committee on Human Rights, 2008) lay out the strategies and the vision for people with intellectual disabilities to be treated with dignity and respect and to have the right support, the same opportunities and responsibilities like any other person. It therefore appears that the plethora of frameworks and policies mentioned above put more emphasis on removing barriers that restrict choices for people with intellectual disabilities. These frameworks may be parallel to the ideals of personal recovery and social recovery discussed above. Significantly, Beresford (2004) provides conceptual clarity that these theories and frameworks have their foundational roots in the social model approach, which is discussed below.

## **2.8 The Social Model Approach**

The social model originates from the disabled people's movement to resist pervasive negative attitudes towards disability. This eventually led to the adoption of a radical stance in the 1970s, which promoted a socio-political explanation (Beresford, 2004) known as the social model (Oliver, 1981). The social model has directed attention away from the medicalised individual model that sees disability from the perspective of deficiencies and incapacities caused by physical, sensory and intellectual impairment. The social model also draws attention to the prejudices and negative attitudes inflicted by the non-disabled majority (Thomas, 2002). The social model approach therefore appears to place less emphasis on clinical recovery, which emphasises elimination of symptoms and the restoration of the former self, as discussed above.

It has been argued that the pervasive prejudice against people with disabilities is a form of social oppression, and the basis of the social model is to highlight the tyranny of social

oppression and promote social understanding in relation to disability (Beresford, 2004). The social model uses a materialistic approach to highlight how the society alienates and prevents people with disabilities from fully participating in economic, political, cultural and social activities (Barnes and Mercer, 2005). Thus, it is possible to argue that the social model approach is located firmly within the inter-conceptual space of personal recovery, social recovery, and policies aiming to promote social inclusion for people with intellectual disabilities.

## **2.9 Concepts of Resilience**

Like recovery, there is no universally acceptable conceptualisation of resilience. However, two variations of conceptualisations can be found in the literature: one narrow and one broad or multi-dimensional. One narrow definition is provided by Bonanno et al. (2005):

‘Resilient individuals typically experience only transient and mild disruptions in functioning (e.g., several weeks of variability in negative affect, difficulty concentrating, or sleeplessness) and exhibit relatively stable levels of healthy adjustment across time. A key point is that although resilient individuals may experience some short-term dysregulation and variability in their emotional and physical well-being...these reactions tend to be relatively brief and to not impede their ability to function to any significant degree. For example, resilient individuals are usually able to continue fulfilling personal and social responsibilities and to maintain a capacity for generative experiences and positive emotions.’ (p.985)

Key points to note in the above definition are that psychological distress is mild, episodic, and brief, lasting a few days or weeks, and then followed by a spontaneous and unaided return to the pre-traumatic state. Moreover, the concept is marked by loss and trauma (Bonanno, 2004). This clearly distinguishes resilience from some conceptualisations of recovery that connote a trajectory in which the individual gradually returns to the pre-illness levels after experiencing mental illness with significant and protracted disruptions in daily functioning.



Full recovery could reasonably be rapid or may take up to 12 to 24 months. The implication is that resilience reflects stability and equilibrium (Bonanno, 2004). True resilience is depicted as robust and unbreakable over time, whilst recovery is connoted by intermittent disruption in the individual's life because of mental illness.

In contrast to the definition above, there are several broad or multi-dimensional constructs of resilience. One of these definitions is provided by the American Psychological Association (2016):

‘the process of adapting well in the face of adversity, trauma, tragedy, threats or significant sources of stress — such as family and relationship problems, serious health problems or workplace and financial stressors. It means “bouncing back” from difficult experiences’.

The conceptualisation above is broad, dynamic, and encompasses many contexts and considerable risk/vulnerability factors, but the central theme is the positive adaptation in the face of challenges. In the same vein, a broader perspective of resilience is adopted by Connor and Davidson (2003), who conceptualise resilience as:

‘the personal qualities that enable one to thrive in the face of adversity...Resilience is a multidimensional characteristic that varies with context, time, age, gender, and cultural origin, as well as within an individual subjected to different life circumstances’. (Connor and Davidson, 2003, p.76)

As with the previous definition, Connor and Davidson's (2003) is broad, dynamic and contextual. The main point is the highlighting of resilience as overlapping psycho-social constructs that determine one's ability to garner strengths, growth and adaptive coping for positive outcomes following exposure to adversity. What is interesting about this definition is its emphasis on the personal, social and cultural background of the individual.

## 2.10 Elements of Resilience

The concept of resilience comprises several factors. Connor and Davidson (2003) compile several salient qualities that make up the concept (table 1). The inferences to be drawn from the table are that resilient people can form solid relationships and social supports; strive to achieve personal or collective goals; demonstrate a greater sense of self-efficacy, humour and self-confidence; exhibit problem solving skills and quickly adapt to adversity; and they are able to have hope and optimism in life.

**Table 2: Characteristics of resilience**

Source	Characteristics
Kobasa, 1979	View change or stress as a challenge/ opportunity
	Commitment
	Recognition of limits to control
Rutter, 1985	Engaging the support of others
	Close, secure attachment to others
	Personal or collective goals
	Self-efficacy
	Strengthening effect of stress
	Past successes
	Realistic sense of control/having choices
	Sense of humour
	Action oriented approach
	Adaptability to change
Lyons, 1991	Patience
	Tolerance of negative affect
Connor and Davidson, 2003	Optimism
	Faith

**Source: Adapted from Connor and Davidson, 2003**

Taken together, the characteristics of resilience can be likened to some of the factors of recovery discussed above. There is a sense that these are both complex and nebulous concepts, although there are salient definitional differences between them.

These concepts have similarities in being defined differently by different authors. Like personal recovery, resilience requires positive emotions and hedonic traits to deal with adversity in life (Mancini and Bonanno, 2006). Resilience in fact mirrors social recovery as it requires a mixture of social, interpersonal and supportive relationships when a person is faced with adversity. However, whilst it is important to possess characteristics of resilience, the capacity to do so can only be determined after the adverse event. This suggests that resilience can operationally be defined as an outcome (Mancini and Bonanno, 2006), which can be assumed as parallel to some conceptualisations of clinical recovery (Silverstein and Bellack, 2008).

### **2.11 Weakening resilience**

According to Shalev and Errera (2008, p.166), certain attitudes and behaviours can potentially have negative effects on resilience. These attitudes and behaviours are shown in Table 3 and further explained below.

**Table 3: Eight ways to to inhibit resilience**

Dramatise Pathologise Catastrophise Create negative expectations Blur boundaries (e.g. between mental disorder and responses) Lie, mislead, misinform or otherwise manipulate information ‘Intervene’ (and emphasise the role of experts) Ignore, show distance or indifference, lack of sharing
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**Source: Adapted from Shalev and Errera, 2008, p. 166**

Dramatise refers to the propensity to exaggerate or give prominence to an emotional turbulence at the cost of facts. Pathologise denotes over-emphasis on potential health

problems, or, for example, over-exaggeration of mental health symptoms. Catastrophise refers to extreme expressions or depictions of normal events as something unheard of. Creating negative expectations refers to the process of delivering information with the pre-ordained intention of expecting negative responses, contrary to the orthodox position of expecting positive reactions. The concept of blur boundaries refers to the normalisation of the fact that everybody is exposed to stressors. Lie, mislead, misinform or the manipulation of information develops from an innate desire to control the recipient's behaviour in order to compromise a provision of information that is reasonable, truthful and reliable; this may ultimately lead to mistrust, confusion and anxiety. 'Intervene' stresses the intervention by a specialist at the cost of the individuals' resourcefulness. All these mistakes can lead to too much attention being given to healing and the medical model of disease rather than adaptation (Shalev and Errera, 2008, p.165-166). It remains to be discovered whether the participants of this study will exhibit any of weakening attributes of resilience discussed above.

## **2.12 Summary**

This chapter introduced the concepts of recovery and resilience. Recovery was discussed as a concept that cuts across disciplines, with each discipline or speciality having its own semantics and important meanings. It was discussed that resilience is developed after repeated exposure to adversity, but defining the concept is also not a simple task. There is also a lack of conceptualisation of recovery from the perspectives of BASUs. Thus, additional empirical research is required to help clarify the construct of recovery and its underlying processes pertaining to BASUs. Chapter three explicitly builds on the central issues discussed in this

chapter and presents a literature review of selected empirical studies on recovery.

## **CHAPTER THREE: EMPIRICAL STUDIES ON RECOVERY**

### **3.0 Introduction**

A vast body of literature pertaining to mental health recovery already exists. Thus, the objectives of this chapter are to present a selective but critical overview of largely empirical studies on recovery from the perspectives of service users, synthesising and discussing key findings. The procedure for conducting the literature review involved the following stages: formulation of including and excluding criteria; development of a search strategy to identify suitable studies; analysis of the quality of the studies reviewed; and synthesis of emerging themes. Thus, the structure of this chapter is organised to follow this process.

### **3.1 Inclusion and Exclusion Criteria of the Literature**

Generally, the quality of any literature review is determined by the comprehensiveness of the search, the validity of exclusion and inclusion criteria and the quality of analysis. Some authorities have suggested that research evidence from systematic reviews, meta-analyses, and original empirical studies are of high quality and more objective than, for example, expert or anecdotal opinions (Aveyard, 2010; Greenhalgh, 2014). Consequently, a decision was made to review only English language publications based on the parameters above. The aim is to synthesise a range of studies over an extensive time frame, whilst utilising the most current empirical knowledge on mental health recovery. Relevant literatures are limited from papers published from 2005 onwards (2005-2015). Additionally, only English language publications are used for pragmatic reasons as time and resources did not allow for translation of non-English publications. This pre-requisite of including literature that is higher on the level of evidence, as well as the imposition of strict inclusion/exclusion criteria will inevitably mean

that much relevant and non-academic literature such as grey literature, anecdotal and service user expert opinion publications, have been excluded, thus introducing a risk of publication bias.

### **3.2 Search Strategy and Data Sources**

The overarching aim was to undertake a thorough and comprehensive search to identify mainly empirical studies on recovery from the perspectives of service users and to help answer the question: what does the scholarly literature say about recovery from the perspectives of BASUs? Hence, four systematic search strategies – electronic database searching, web-based searching, hand-searching and personal networks – were utilised to identify the relevant literature. These strategies are explained below.

#### **3.2.1 Electronic Database Searching**

The following databases were searched using the NICE Healthcare Databases advanced search (HDAS) platform: AMED (Allied and Complementary Medicine), BNI (British Nursing Index), CINAHL (Cumulative Index of Nursing and Health Literature), EMBASE (Excerpta Medica Database), HMIC (Health Management Information Consortium), Medline and Psych INFO. All databases were searched from 2005 to 2015 using the following search terms:

- A. 'Interpretative phenomenological analysis' or 'IPA'
- B. 'Mental health' or 'mental disorder\*' or 'mental illness\*' or 'mental disease\*' or 'mental problem\*' or 'mental health problem\*'
- C. 'Recovery\*' or 'recover\*' or 'recovering' or 'rehabilitation\*' or 'survival\*'
- D. 'African' or 'Black African' or 'Sub-Saharan African\*'

- E. 'Minority\*' or 'ethnic\*' or 'ethnic minority\*' or 'BME' or 'BME groups' or 'Black and minority ethnic groups'
- F. 'Afro-Caribbean' or 'African-Caribbean' or 'Caribbean'
- G. 'Hope\*', 'healing\*', 'spirituality\*'; 'empowerment; connection' or 'social network\*' or 'support\*' or 'social support; self-control' or 'control\*'; 'resilience\*'; 'medication\*'
- H. 'Qualitative' or 'qualitative research; narrative review'
- I. 'Systematic review' or 'meta-analyses' or 'quantitative'

The search was adapted for the individual databases and interfaces as required. For example, terms were mapped to a thesaurus when available in the databases. None of these presented studies about the experiences of Black African service users recovering from mental illness in England, thereby suggesting a gap in the literature. Appendices 10 and 11 provide examples of the database search and results in CINAHL and BNI respectively.

### **3.2.2 Web-based Searching**

Internet searches using Google and Google Scholar were utilised to identify relevant literature on recovery. Specific recovery-oriented websites such as the Recovery Devon (<http://www.recoverydevon.co.uk/>), Social Perspectives Network (<http://www.spn.org.uk/>), the Scottish Recovery Network (<http://www.scottishrecovery.net/>), Boston University Centre for Psychiatric Rehabilitation (Repository of Recovery Resources) (<http://cpr.bu.edu/resources/recovery-repository>), the Center for International Rehabilitation Research Information and Exchange (CIRRIE) (<http://cirrie.buffalo.edu/>) and Trip (<http://www.tripdatabase.com/>) were also used to search for literature.



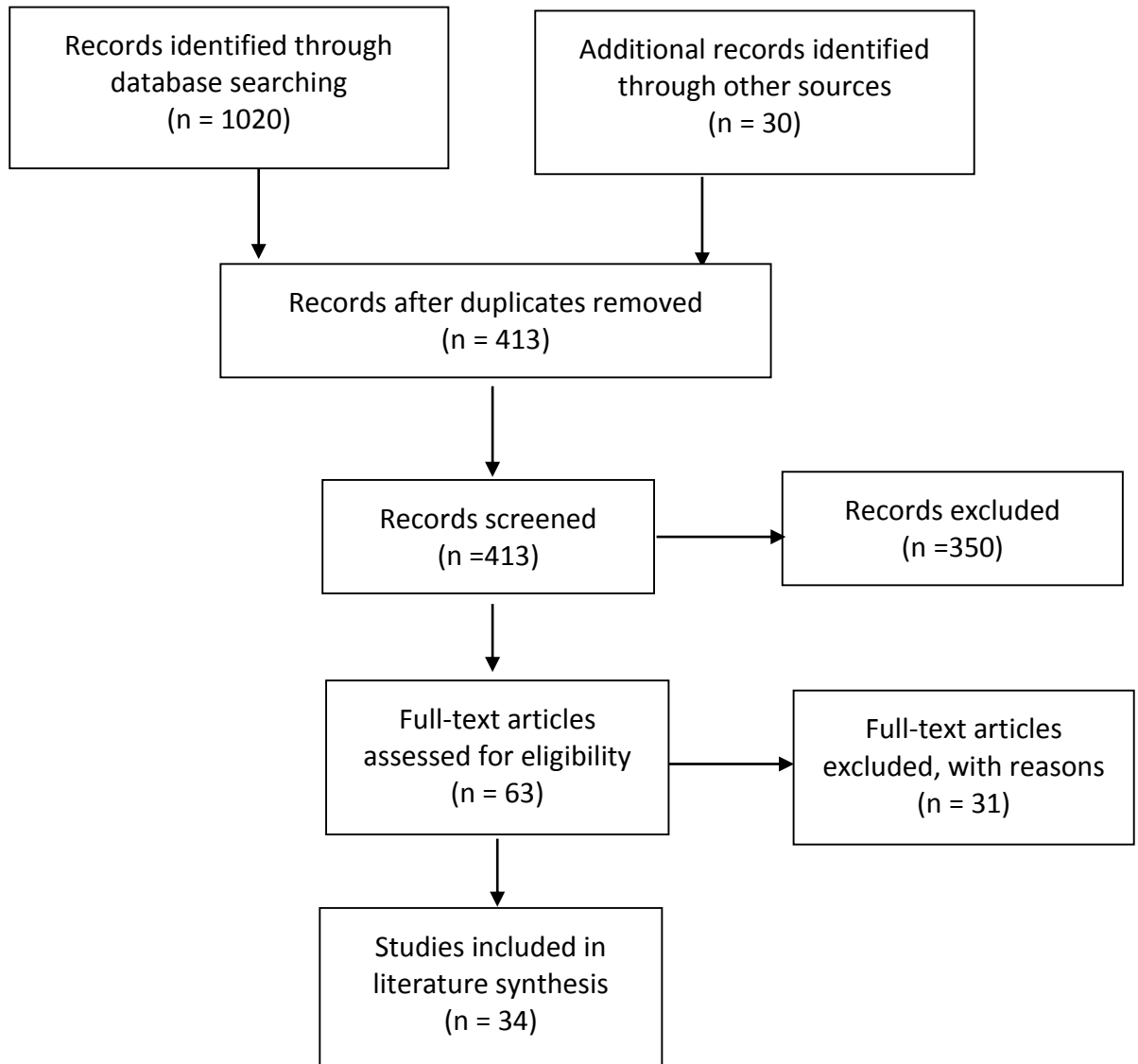
### **3.2.3 Hand-Searching and Personal Networks**

Hand-searching the table of contents for mental health journals and other journals that publish recovery-related articles, as well as recent literature reviews of recovery, abstracts of conference proceedings and citation lists of all articles were utilised for relevant references. Additional articles were identified through personal networking.

### **3.3 Results of Literature Search**

A total number of 1,020 potentially relevant articles were identified from the database search. These included: AMED – 100 citations; BNI – 133 citations; CINAHL – 224 citations; EMBASE – 141 citations; HMIC – 89 citations; Medline – 127 citations and Psych INFO – 206 citations. Additionally, 60 articles were identified through web-based searching, hand-searching and personal networks. After duplicates were removed, a total of 350 articles were excluded from the review because they didn't meet the inclusion criteria. The remaining 34 articles comprised 20 qualitative studies, five quantitative studies, four systematic reviews, and three mixed-methods studies. 10 of the papers originated from the USA, nine from Britain, three from Canada, two from Australia, two from South Africa, four of the articles were multinational and/or a review of international studies, and one each was from Ireland, Norway, Nigeria and Sweden. The studies reflected a broad range of disciplinary orientations located within social work, occupational therapy, psychiatry, and mental health nursing. The results of the search findings are summarised in Figure 2.

**Figure 2 - Literature search results**



### **3.4 Methods of Critical Appraisal of the Literature**

The quality of any literature review depends on the quality of the studies included. Therefore, the relevance of the selected literature was initially evaluated by reading abstracts and text introductions to ascertain their significance to the research question, and to check against the inclusion and exclusion criteria (Aveyard, 2010). Additionally, prior to the synthesis of the literature findings, a methodological appraisal of the selected studies was conducted. There is a wide range of qualitative appraisal tools to choose from, thereby highlighting the lack of consensus on how to appraise a qualitative research. For example, one study identified over one hundred appraisal tools (Noyes et al., 2010). Such multiplicity raises concerns about reducing qualitative research to a list of technical procedures (Barbour, 2001). A range of different methodologies were included in this review, therefore the Critical Appraisal Skills Programme (CASP) was chosen to guide the evaluation of the selected literature. CASP was chosen because of its specific design, focused on appraising empirical studies and its ability to assess the trustworthiness, relevance and results of published literature in a standardised way. CASP has a set of eight critical appraisal tools and each tool has a distinctive way to evaluate research (CASP, 2013).

### **3.5 Approaching a Synthesis of the Literature**

Given the mixture of research approaches that emerged from the literature search, the 'simplified approach' (Aveyard, 2010) that allows for a combination of results of studies with different research methodologies was chosen. The 'simplified approach' involves comparing each study, assigning codes to the main findings/discussion points, developing themes, comparing the codes and themes, and scrutinising codes and themes (Aveyard, 2010). The

following sections present an in-depth synthesis of the results from the literature. This is grouped and discussed in greater detail under three main themes: empirical recovery studies on BASUs; empirical recovery studies on BME service users; and empirical studies on personal and social recovery.

### **3.6 Empirical Recovery Studies on BASUs**

Five studies exploring the recovery experiences of service users, and recovery-oriented services from Sub-Saharan Africa were identified. One such study is an experimental quantitative study conducted in Nigeria by Gandhi and Wai (2010) to ascertain how medical, psychological, and social interventions impact recovery. 56 service users from various socio-cultural indigenous groups in one state in Nigeria were randomly assigned to two comparable groups: the experimental and the control group. The experimental group was exposed to medical, psychological and social interventions for three months, whilst the control group only had medical treatment within the same time frame. The main outcome measure revealed that the experiment group showed signs of recovery more than the control group. Thus, Gandhi and Wai (2010) concluded that complete recovery from mental health problems is possible if people have access to appropriate medical and professional interventions, as well as social support. Thus the authors identify clinical and social recovery as important notions of recovery for the participants. However, as a very small study with a short intervention and no follow-up, caution must be applied to such a conclusion.

Unlike in a qualitative approach, the subjective experiences of the participants in the research discussed above were not adequately explored. However, Gandhi and Wai (2010) demonstrate good sensitivity to the context by reviewing the relevant literature and previous studies and

linking them to their study. The authors also demonstrate sensitivity to the cultural context by recruiting participants from various socio-cultural groups in one geographical area in Nigeria. Though the authors do not mention how they obtained ethical approval for the study, they show commitment to the quantitative approach by providing a thorough description of how data was collected and analysed. The authors also mention triangulation of data by using secondary sources including sources from the literature and textbooks. Whilst this triangulation of different data and/or methods in the study offers the ability to cross check evidence and assist in the research design, questions may be raised about the quality and appropriateness.

In a different study employing an IPA methodology, de Wet, Swartz and Chiliza (2015) conduct semi-structured interviews with seven South African participants comprising six Coloured (sic) people and one White person in order to ascertain their experiences of recovery from first-episode psychosis in schizophrenia. The authors find that support and the need to care for another are the important contributory factors for the participants' recovery. Spirituality and rediscovery of abilities are also found to be vital to the participant's recovery. However, stigma is found to be prevalent and a barrier to participants' recovery. A notable weakness of this study is the failure by the authors to clearly specify the aims and relevance of the study. However, de Wet et al. (2015) remedy this by demonstrating sensitivity to context by reviewing the relevant literature and relating it to their study. They also describe how ethical approval was obtained for the study and the authors demonstrate commitment and rigour by explaining the procedure for collecting data, as well as presenting a coherent analysis of the data. However, the analysis of the data is mainly descriptive and not sufficiently

interpretative, as required in IPA research. Finally, although the need to study BASUs' perspectives of mental health recovery is explicitly recognised in the study, the results need to be interpreted with caution due to the ambiguity and negative connotations surrounding the actual composition of the participants. The authors use the term 'Coloured', thereby not making it explicit whether they are including Black people. Further, 'Coloured' was arguably a pejorative term in the USA and South Africa during the period of racial segregation and apartheid respectively, used to describe non-Caucasians or persons with mixed racial heritage. Notably, Lander (2010) points out that the term is considered negative and carries inferiority connotations, particularly as non-white South Africans were assigned inferior amenities during the Apartheid era.

To gain insights and use them as a yardstick for the implementation of a recovery-oriented approach elsewhere in Africa, Kleintjes, Lund and Swartz (2013) present a qualitative study reporting on the principal strategies of how nine national self-help organisations in seven African countries promote recovery for people with mental illness. The authors undertake semi-structured interviews with four women and seven men who are leaders of national mental health organisations in Ghana, Kenya, Rwanda, South Africa, Tanzania, Uganda and Zambia. Kleintjes et al. (2013) report that sustainable and organisational strategies including advocacy of destigmatising mental disorders, rebuilding the service users' lives to improve their lives in the community and access to health services, social support, and legislative and policy reform were some of the core works of these organisations. Thus, the authors conclude that self-help organisations can play a vital role for service users in Africa recovery.

There are two notable drawbacks to the above study. One, the authors do not specify the

type of qualitative approach they use, and two, the study participants do not include any service users, whose perspectives about recovery and mental health services in Africa are vital. However, Kleintjes et al. (2013) demonstrate good sensitivity to the context by carefully reviewing the relevant literature and previous studies and linking them to their study. Moreover, carrying out the research across seven African countries shows a solid cultural sensitivity. An account is also given of how ethical approval was provided by the relevant research ethics committee. The study demonstrates commitment to the qualitative approach by describing methods of recruitment, data gathering and analysis. Furthermore, the authors demonstrate commitment to the qualitative approach by presenting in-depth descriptions of their data collection and analysis procedure to produce a coherent and strong narrative from the data.

Kleintjes et al. (2012) utilise a phenomenological study to document the South African service users' views on policy directions and service developments supporting recovery. The authors conduct semi-structured interviews with 40 service users, comprising 20 advocates and 20 non-advocates. The authors find that issues about stigma, discrimination and disempowerment, as well as mental health related poverty are the dominant themes reported by the participants. In their conclusion, Kleintjes et al. (2012) suggest that service user involvement, empathetic alliances and empowering partnerships are some of the important strategies that could be adopted to bridge the gap between the rights and needs of service users, pejorative attitudes, policies and practices.

Kleintjes et al. (2012) demonstrate good sensitivity to the context by reviewing the relevant literature. The authors appropriately use purposive sampling and demonstrate sensitivity to

the socio-cultural setting by interviewing participants in their native language where necessary. They also describe the procedure for obtaining ethical approval, informed consent and assurance of confidentiality from the participants. They demonstrate commitment to the qualitative and phenomenological approach through a transparent and coherent approach to data collection and analysis of emerging themes. They also show cultural sensitivity by seeking narratives in the participants' native languages. However, a notable weakness is the failure to explore the participants' lived-experiences of mental illness and recovery. Moreover, it is possible that some core insights of the participants' narratives were lost during translation of some of the interviews from native languages into English.

In summary, all the papers reviewed thus far have produced novel insights and perspectives on recovery in the Sub-Saharan African context. However, many do not explicitly explore the lived-experiences of the participants. Moreover, insights from the participants and findings are specifically linked to Africa. It is possible that the views, insights and experiences of BASUs in Africa and England might be different due to geographical differences. The section below is a critical review of empirical recovery studies on BME service users.

### **3.7 Empirical Recovery Studies on BME Service Users**

What we know about BME service users' recovery is largely based upon a few empirical researches conducted in a limited number of Anglophone countries. One such research is a mixed-methods study by Armour, Bradshaw and Roseborough (2009) that examined the lived experiences of nine African Americans recovering from serious and persistent mental illnesses. For the quantitative data, the authors collected psychological measures on demoralisation, engulfment and coping, whilst semi-structured interviews guided by a



hermeneutic phenomenological approach was utilised to elicit the subjective experiences of the participants. Both quantitative and qualitative data were collected at intervals of 6, 12 and 18 months. The results of the qualitative and quantitative analysis reveal that even though most of the participants had faced the challenge of persistent social adversity, such as probation, homelessness, poverty and discrimination, many utilised various complex coping strategies embedded in their community, family, church and profession to help with their recovery. The findings suggest that the participants conceptualised their recovery in the context of their relationships and social support. This is consistent with studies reviewed below (section 3.10.4) that all suggest recovery can ensue in a social context.

Armour et al. (2009) report that there were undertones from the participants' narratives that their experiences of stigma and discrimination might stem from their race or mental illness. However, this account must be approached with some caution as an important point that is sometimes overlooked is that negative experiences are not only confined to Black people. For example, it has been reported that many White service users from Ireland and Eastern Europe living in England have experienced stigma and discrimination (Care Quality Commission, 2014). It is interesting to find whether the participants in this thesis identify with such negative experiences.

Armour et al. (2009) fail to specify how ethical approval was gained for the study. Despite this weakness, the authors demonstrate good sensitivity towards the context by thoroughly reviewing the relevant literature and previous studies and linking them to their study. The strength of the study lies in its adoption of an Afrocentric perspective in the qualitative analysis. Afrocentricity traces its theoretical heritage to African culture and specifically

situates its analysis in African cultural backgrounds (Asante, 2007). Armour et al. (2009) therefore demonstrate cultural sensitivity in the study. The authors also demonstrate commitment to the mixed methods approach by providing an in-depth description of their data collection and analysis procedure to produce a coherent and strong narrative from the data. Another innovative aspect of this research is the assurance of validity using anonymous African-American research clinicians to review and critique the data analysis. This study provides an example of how a qualitative and particularly phenomenological method can be used to complement quantitative research and explore the experiences of the participants. The homogeneity of the study sample provides a very good strength for the study, and it can be argued to provide a benchmark for this thesis. Armour et al. (2009) also demonstrate evidence of research to practice by discussing clinical implications of the findings. Perhaps a minor drawback of this study is that it was conducted in the American context. It could be argued that due to vast cultural differences, the findings may not necessarily be applicable to Black service users in England.

In another study, Brijnath (2015) conducted qualitative interviews with 30 Anglo-Australians and 28 Indian-Australians living with depression in Melbourne, Australia with the aim of applying connectedness, hope and optimism about the future, identity, meaning in life and empowerment (CHIME) to these two culturally diverse groups. Whilst the various components of CHIME were found to be important to both groups, many identified stigma and lack of social support as disturbing trends in their experiences. The participants linked recovery with identity, hope and optimism, positive thinking, cure and discontinuing treatment. This suggests that the participants had both personal and clinical recovery in mind.

The findings are also consistent with studies by Davidson and Roe (2007) and Piat et al. (2009) (see below) that suggest that different forms of recovery may simultaneously exist in the minds of some service users. Again, Brijnath (2015) found that the Indian-Australians in particular felt affinity with spirituality, whilst the Anglo-Australians derived meaning from the illness experience. This leads the author to conclude that culture can mediate the operationalisation of the sub-components of CHIME.

A notable weakness of this study is the failure by the author to make explicit the type of qualitative approach adopted for the study. Despite this, Brijnath (2015) demonstrates satisfactory sensitivity to context by reviewing the relevant literature and relating it to the study. There is also a clear description of how ethical approval was obtained and the study demonstrates commitment to the qualitative approach by describing methods of recruitment, data gathering, and analysis.

A notable recent empirical research that has advanced our knowledge of the multidimensional meaning of recovery from the perspectives of BME service users is a study by Kalathil (2011). The author interviewed 27 African, African Caribbean and South Asian women from London, who identified themselves as service users or survivors, to explore their unique stories of distress and recovery from mental health problems. Data was analysed thematically without considering the ethnic backgrounds of the participants. The author finds that the participants' perspectives of recovery are intrinsically connected to their perceptions of their mental distress, which stem from adverse life events, socio-political oppression, spiritual crises, trauma and stress. Interestingly, Kalathil (2011) explains that facilitating a positive sense of self is only possible if the participants' life history is contextualised in the

recovery process.

The need for exploration of BME perspectives of mental health recovery in England is overwhelmingly recognised in the above study. Although the study appears to be thoroughly carried out with authoritative sources and in-depth analysis, however, it suffers from the fact that it has not been published in a peer reviewed journal, and therefore has not been subjected to peer review scrutiny. Another weakness is that thematic analysis of data is deprived of the ethnic backgrounds of the participants. This might introduce a risk of grouping and discussing experiences of all BME service users' together regardless of their racial and cultural backgrounds. Despite this, Kalathil (2011) demonstrates good sensitivity to context by reviewing the relevant literature and relating it to the study. Furthermore, an account of how ethical approval was gained from the relevant research ethics committee is given and the study demonstrates commitment and rigour to the qualitative approach through descriptions of data collection, analysis and validation of emerging themes.

To summarise, the above section highlights the studies relating to BME service users. The key strengths of these studies are bringing to the forefront the important nuances pertaining to BME service users' recovery from mental illnesses. The following section describes synthesis and evaluation of empirical studies on personal recovery.

### **3.8 Empirical Studies on Personal Recovery**

This section presents literature findings, interpretation and critiques of empirical studies on mental health recovery in the context of concepts of personal recovery and social recovery.

### **3.9 The Concepts of Recovery**

The consensus from the previous chapter was that recovery is an elusive construct, yet the concept is now the bedrock for the mental health policy in many Western countries. Thus, several empirical studies have attempted to conceptualise recovery from the perspectives of both service users and mental health professionals. For example, in a qualitative analysis, Le Boutillier et al. (2011) undertake semantic-level, thematic analysis of 30 international recovery-oriented practice guidance documents from six countries – the United States, England, Scotland, Republic of Ireland, Denmark and New Zealand, with the aim of understanding the meaning of recovery from international perspectives and developing a comprehensive conceptual framework for recovery-oriented practice. Four dominant themes emerged: promoting citizenship, organisational commitment, supporting personally defined recovery, and working relationships. Le Boutillier et al. (2011) report that promoting citizenship entails supporting and empowering service users to integrate into the society and engage in meaningful occupation and social roles. Organisational commitment refers to demonstrations that the work environment and service structure are conducive to promoting recovery-oriented practice. Supporting personally defined recovery involves maintaining focus on the individual service user in order to identify their personal choices and goals and promote autonomy; working relationship entails therapeutic relationships and the ability to support service users to accomplish their goals in life and to shape their own future.

A major drawback of the above study is that it uses a non-systematic approach to identify the guidance documents, a limitation the authors themselves note. Moreover, the documents included in the synthesis are not necessarily empirical or primary research materials and they

do not conform to hierarchies of evidence in research (Aveyard, 2010; Greenhalgh, 2014). The major strength of the study is the commitment and rigour as Le Boutillier et al. (2011) take a series of steps to explain the research process, the rigorous systematic search strategies, and the approach to the synthesis of data. This makes it easy for a novice researcher to follow and learn the process.

To date, the most comprehensive conceptualisation of personal recovery comes from a systematic review of available international literature on personal recovery by Leamy et al. (2011) whose main aim is to develop a new conceptual framework for recovery using modified narrative synthesis. The authors review 97 papers from 5,208 identified papers. The resulting conceptual framework of personal recovery consists of 13 characteristics of the recovery journey and five interrelated recovery processes: connectedness, hope and optimism about the future, identity, meaning in life and empowerment, or the acronym, CHIME. The claim that this was the first systematic review and narrative synthesis of personal recovery may be viewed as a strength in presenting robust and useful summaries to gain an in-depth understanding of personal recovery.

The above finding is consistent with a similar study by Slade et al. (2012) who employ a modified and updated systematic review to validate the conceptual framework of Leamy et al. (2011), and to identify country distribution, scientific foundations and the weight put on recovery conceptualisations. They identify 7,431 papers and review 429 full papers, from which 105 conceptualisations of personal recovery are identified from 115 papers, mainly from the USA (47%) and the UK (25%). Slade et al. (2012) find relatively similar results to those obtained by Leamy et al. (2011), discussed above. However, this result may be explained by

the fact that Slade et al.'s (2012) work is an 'update and modification' of that of Leamy et al. (2011). Moreover, the composition of the authors in both projects is nearly the same. It is also not possible to be clear how linguistic and cultural differences across countries are accounted for in these two studies. The methodological and conceptual flaw of these studies is that emergent themes are synthesised from analysis of already published data, thus posing a risk of replicating misleading outcomes in the original studies (Greenhalgh, 2014).

Despite this, there are strengths that come with these two studies. For example, the demonstration of robust search strategies and the systematic selection and appraisal of studies in accordance with an approved protocol means that bias is minimised. Both Slade et al. (2012) and Leamy et al. (2012) show strengths in cultural sensitivity by incorporating studies on recovery for individuals from BME groups. Therefore, their results are likely to be robust and generalisable. The most striking outcome to emerge from these reviews is the discovery that scientific foundations on personal recovery are predominantly qualitative studies. This demonstrates that the qualitative methodology remains the most appropriate approach to explore people's experiences of recovery from mental illness. More importantly, Leamy et al. (2011) and Slade et al. (2012) both demonstrate evidence of research to practice by highlighting the need for studies in recovery involving diverse ethnic minority communities. Accordingly, the present research uses IPA to explore the meaning of recovery from the perspectives of BASUs in England.

Several qualitative studies conceptualising personal recovery have been carried out recently. One such study is by Piat et al. (2009), who employ semi-structured interviews to explore the perspectives of 60 service users receiving care from the Canadian Mental Health Services with

regard to the meanings of their mental health recovery. The authors find two contrasting meanings of recovery: medical (clinical) and psychosocial. The medical (clinical) recovery is strongly attached to illness, where the participants overwhelmingly identified recovery with cure, medication or returning to a former self. Contrarily, the participants associated a psychosocial meaning of recovery with self-determination and self-responsibility, and as a process that evolves into a new self. In effect, the results show that there is a need for a compromise between these two perspectives. The suggestion that different forms of recovery may co-exist in the minds of some service users is consonant with other studies (Davidson and Roe, 2007). However, it has also been suggested that service users usually place emphasis on personal recovery (Bellack, 2006; Davidson and Roe, 2007; Slade, 2009; Silverstein and Bellack, 2008). It remains to be discovered whether the participants in this study ascribe to medical (clinical) definitions, psychosocial definitions, both definitions, or something else.

Piat et al. (2009) demonstrate good sensitivity to context by conducting a thorough review of the relevant literature and previous studies and relating them to their study. The authors provide a clear exposition of the purpose of their study and show transparency and a coherent approach to data collection and analysis. They also describe how ethical approval was gained from the relevant research committee and how they gained consent from the participants. The authors particularly show accountability in their study by appointing an advisory committee to oversee the study. The sample size of the study may also be viewed as a strength and may have contributed to the credibility and validity of the study; however, this equally may have hindered an in-depth analysis of the data considering that qualitative studies aim to explore the meanings participants assign to their experiences. Moreover, Piat



et al. (2009) do not specify the type of qualitative approach used in the study and although they report that the participants are from diverse geographic, socio-demographic, linguistic backgrounds, they provide no detailed demographic information about the individual participants. Despite these minor flaws, this qualitative study provides a valuable contribution to our understanding of the dual conceptualisation of personal recovery.

In another study about conceptualisation of personal recovery conducted in Canada, Windell, Norman and Malla (2012) employ the IPA methodology to conduct semi-structured interviews with 30 individuals comprising 27 Caucasians, one Asian, one Black and one First Nations or Native American, all of whom had experienced their first episode of psychosis, in order to determine their personal definitions of recovery. The authors found that the participants described recovery in one or more of the following domains: illness recovery, psychological and personal recovery, or social and functional recovery. The findings are consistent with the multi-dimensional approach of recovery by Whitley and Drake (2010), as well as the study by Piat et al. (2009) who found two contrasting meanings of recovery: medical (clinical) and psychosocial.

However, the study suffers from some weaknesses: the authors exhibit poor sensitivity to context by not demonstrating meticulous development of ideas, which is noticeable in the limited review of relevant literature pertaining to the study. Although Windell et al. (2012) provide a description of methods of data collection and in-depth analysis of emergent themes, they show limited rigour in terms of explicit expositions of fundamentals of IPA. In particular, it could be argued that their larger sample size than a typical IPA study potentially prevents idiographic analysis of emergent themes.

Most of the studies reviewed thus far have concentrated on conceptualisations of recovery from the perspectives of service users. However, recent evidence suggests that conceptualisations of recovery by mental health professionals may differ from that of service users. In a study carried out in England, Le Boutillier et al. (2015) undertake a systematic review and narrative synthesis of empirical studies with the aim of identifying how clinical staff and managers conceptualise recovery. 22 papers involving 1,163 participants are reviewed. Three themes emerge about conceptualisation of recovery: clinical recovery, personal recovery and service-defined recovery. The authors conclude that service-defined recovery is a new conceptualisation that incorporates the ideals of recovery into practice based on the goals and financial circumstances of the organisation. The authors therefore suggest that the service-defined recovery is a cost reducing tool to help meet organisational targets. The insight from the study by Le Boutillier et al. (2015) is that the extent of the recovery-oriented programme in a given organisation is dependent on its financial power.

Like the systematic review and narrative synthesis studies above, the results in Le Boutillier et al.'s work are derived from already published data, thus posing a risk of replicating misleading outcomes in the original studies. However, the study does help to provide an insight into the ulterior motives for organisational support for recovery-oriented services. Moreover, the strengths of the paper by Le Boutillier et al. (2015) are that the review addresses a clearly focused question, and there is a demonstration of transparent and rigorous systematic search strategies and quality assessment to identify qualitative research studies for the review. The assertion that this is the first systematic review and narrative synthesis of staff conceptualisations and perspectives of recovery-oriented practice may be

viewed as a strength.

Similarly, in a grounded theory study conducted in England, Le Boutillier et al. (2014) use 10 focus group interviews involving 34 multidisciplinary clinicians and 31 team leaders, and individual interviews with 18 clinicians, six team leaders, and eight senior managers to investigate staff views about their support for recovery and their perceptions of barriers and facilitators of a recovery-oriented approach. Three conflicting sub-categories about how a recovery-oriented approach is implemented emerge: health process priorities (where the meaning of recovery is influenced by the health infrastructure and culture), business priorities (where the financial commitment of the organisation influences the meaning and implementation of recovery-oriented practice) and staff role perception (where staff work commitments influence recovery-oriented practice). In my view, the emergent categories from the study suggest a controlling mental health system in which the voices of its service users are stifled in their attempts to determine subjective meanings of recovery.

Le Boutillier et al. (2014) demonstrate rigour and transparency by presenting a detailed description of how they obtained the ethical approval for their study. They also provide in-depth information on recruitment of the sample and the data collection process. Furthermore, there is a coherent and strong analysis of the data that is manifested in clear themes to produce an innovative insight into factors affecting the recovery-oriented service from the perspectives of clinical staff and managers. However, the authors do not specify the ethnic composition of the participants.

In sum, the empirical studies reviewed thus far have revealed the level of ambiguity and lack

of consensus surrounding the meaning of personal recovery as it is understood by service users and professionals alike. The studies reveal insights about service-defined recovery. Personal recovery is defined as not just an ongoing process and/or life experience, but also as a clinical recovery or absolute cure from symptoms. There is also an implication that some services users may harbour different understandings of recovery. The strengths of these studies are that the divergence and ambiguities themselves originate from the voices of the recovering people. It is precisely these voices that must tell us how recovery from mental health illness should be defined. However, rather disappointingly, the studies reviewed above show that far too little attention has been paid to the voices of Black service users.

Whilst the naive assumption could be that Black service users are not being selected to participate in studies, several factors such as health illiteracy, attitudinal and sociocultural factors (Farmer et al., 2007), and mistrust of the healthcare system due to genuine concerns about being harmed or exploited (Calderon, 2006; Scharff et al., 2010) have been cited as factors affecting research participation amongst Black people. It is important to point out that the mistrust of the healthcare system mostly originates from the USA due to negative historical events such as more than four centuries of medical exploitation of Black people (Scharff et al., 2010; Washington, 2006). Next, a selective but more detailed examination and evaluation of the empirical research focusing on some aspects of personal recovery is explored.

### **3.10 Processes of Personal Recovery**

As noted above, the resulting conceptual framework discussed by Leamy et al. (2011) and Slade et al. (2012) identifies key features of personal recovery. Some of these key features,

such as hope, self-control, empowerment, choice and spirituality, are explored in the following sections.

### **3.10.1 Hope**

Several empirical studies have demonstrated that hope can play a vital role in personal recovery. For example, in an IPA study conducted in Britain, Sagan (2015) employs narrative interviews to explore the meaning making of 40 people with mental difficulties engaging in an ongoing visual art practice. The participants comprise 25 women and 15 men who self-identify as White British, Black African, Indian Asian, European, American and South East Asian backgrounds. The author finds that even though the artistic activity provides a springboard for the participants' autobiographical analysis, hope plays a central role in the participants' enterprise.

As with the findings by Hobbs and Baker (2012), the study by Sagan (2015) suggests that interpersonal and relational factors can influence hope after a first episode of psychosis. However, the study suffers from some shortcomings as the author fails to describe some vital procedures involved in the research. For example, the author does not explicitly state how ethical approval for the study and informed consent from the participants was obtained. Also, the author does not specify the number of each ethnic group that participated in the study. However, the work's strength is in the fact that the various participants reflect on the multicultural diversity and perspectives of service users in Britain. Furthermore, the author demonstrates good sensitivity to context by reviewing and linking the relevant literature to the study. The author also demonstrates rigour and commitment to IPA by clearly explaining the rationale for their choice and the various stages of the methodology. The study

demonstrates the value of IPA as a research methodology in helping to develop an understanding of idiosyncratic and complex issues of recovery.

In an IPA study conducted in Britain to explore the influences of hope on personal experiences following a first episode of psychosis, Perry, Taylor and Shaw (2007) employ semi-structured interviews to explore the experiences of five male White British participants within eight months of their first episode of psychosis. As with the findings by Hobbs and Baker (2012), the authors find that interpersonal and relational factors can influence hope after a first episode of psychosis.

However, the above study suffers from some shortcomings as the authors fail to describe some vital procedures involved in the research. For example, they do not explicitly state how ethical approval for the study and informed consent from the participants was obtained. Participant selection bias is another potential concern as Perry et al. (2007) rely on psychiatrists to identify participants. Despite all these weaknesses, the authors demonstrate a good sensitivity to context by reviewing and linking the relevant literature to their study. The authors also demonstrate rigour and commitment to IPA by clearly explaining the rationale for their choice and the various stages of the methodology. The study demonstrates the value of IPA as a research methodology in helping to develop an understanding of the idiosyncratic and complex issue of recovery. However, the findings may not necessarily be applicable to female service users given that the composition of the participants is all males. Nonetheless, the authors are justified in concluding that the quest for meaning and belongingness are fundamentally associated with hope. As will be seen below, empirical researches have shown that social support and networks can facilitate recovery.

A pilot study in the USA by Waynor et al. (2012) to assess the relationship between hope and mental illness in a group of 74 service users comprising 44 Caucasian (59.5 percent), 25 African Americans (33.8 percent), two Hispanic (2.7 percent) and three Others (4.3 percent) finds a strong inverse relationship between hope and symptoms. The authors also find a significant positive relationship between hopelessness and symptoms. Consequently, Waynor et al. (2012) conclude that experiences of psychiatric symptoms can lead to a decrease in hope. A legitimate conclusion is that because mental illness impacts negatively on feelings of hope – it can make people feel hopeless and even suicidal – people have identified that when others instil hope it helps in their recovery (Leamy et al., 2011; Slade et al., 2012; Piat et al., 2009; Windell et al., 2012). The scant review of the relevant literature by Waynor et al. (2012) shows poor sensitivity to context and the authors fail to provide a justification for the sample size and fail to discuss whether the participants were randomly selected or not. Despite this, the authors demonstrate strength in their sensitivity to the socio-cultural diversity of the participants. They show commitment and rigour to the quantitative approach by providing a detailed, in-depth description of procedures, measures and methods of statistical analysis.

In summary, the papers reviewed above posit that hope is fundamental in personal recovery. Synthesis from the literature reveals that hope can be influenced by social and interpersonal relationships. Disappointingly, studies were found to be limited in diversity from multicultural perspectives. Although the need for BME perspectives was tacitly recognised in some of these studies, it was not sufficiently demonstrated. The following section presents a selective but more detailed examination and evaluation of the literature, focusing on the empirical research on empowerment and choice as enablers of personal recovery.

### **3.10.2 Empowerment and Choice**

Numerous studies have been conducted that reveal that many service users wish to be empowered to make their own personal choices. One such study is a grounded theory study conducted in the USA by Mancini (2007). The author conducts in-depth semi-structured interviews with 16 survivors of mental health problems, comprising 14 Caucasians, one African American and one Latin American, to discuss critical turning points in their recovery processes and to establish how recovery can be initiated and advanced. Findings reveal that the participants define their turning points and recovery as a transformation from 'disabled' dominated identities to identities dominated by agency and empowerment. As a result, Mancini (2007) concludes that empowerment and self-control can play a vital role in personal recovery. The idea that empowerment pervades a sense of agency for many service users who feel disadvantaged due to disability and a lack of opportunities in their lives suggests that it can be used as a standard of change for many service users to fully integrate into the society.

Mancini (2007) shows good sensitivity to context by reviewing the relevant literature on transformation and recovery and links them to his study. He also demonstrates commitment and rigour, transparency and coherence by clearly outlining data collection procedures and analysis of emerging themes. Though the author does not make it clear the procedures for obtaining informed consent from the participants, a noteworthy strength of the study is the use of a grounded theory approach that allows themes to emerge from the data rather than the research being influenced by pre-existing hypothesis held by the researcher. However, notable limitations of the study are issues surrounding the methodology; for example, specific components of grounded theory, such as theoretical sampling and saturation of data, are not



clearly specified by the author. Moreover, participants were recruited from consumer-operated services and might have been well connected to the already functioning recovery-oriented services. Another weakness of the study is the unrepresentative nature of the mental health service users. Perhaps, in this regard multicultural perspectives of what empowers service users' recovery are particularly necessary.

In another qualitative study conducted in the USA focusing on the lives and wishes of service users in a user-led project, Davidson et al. (2010) utilise narrative interviews that focus on the lives, wishes and role of the mental health services for 80 participants. The findings reveal the participants' profound senses of loss, despair and disorientation about their existence when speaking about their wish to have the luxury to choose the most important things in their own lives. The authors show strength in sensitivity to rigour, transparency and coherency by providing in-depth descriptions of the procedure for obtaining ethical approval, a step-by-step description of methods of data collection and rich analysis and interpretation of emergent themes. The large sample size of the study is strength, but this could have equally restricted exhaustive analysis of the data. Although Davidson et al. (2010) report that qualitative analysis was used to identify key themes from the first 30 interviews, they fail to explain what happened to the views of the other 50 participants who took part in the study. The limited review and interpretation of the relevant literature pertaining to their study indicates poor sensitivity to context. The authors also fail to specify the composition of the study participants, and therefore we do not know if the study outcome reflects the views of BME and particularly Black African service users. Despite these shortcomings, the outcome of this study suggests that one of the unique ways to enhance recovery is to empower service

users to have the authority to make choices and decisions affecting their lives (Slade et al., 2008).

In another study, McEvoy et al. (2012) use mixed methods and telephone interviews with 98 service users comprising 94 White British and four Non-White British service users with diagnoses of common mental illnesses such as depression and anxiety disorders to understand their perspectives of the meaning of recovery. The data collection procedure involves quantitative and qualitative data collections. The quantitative data collection includes an evaluative telephone survey outlining the subjective rating of the participants' performance (on a scale of one to ten) of each of the 10 Mental Health Recovery Star domains (managing mental health, self-care, living skills, social networks, work, relationships, addictive behaviour, responsibilities, identity and self-esteem, and trust and hope) (MacKeith and Burns, 2010). The qualitative interviews are centred around the three biggest shifts in the participants' scores in their subjective ratings of the Recovery Star domains. A central theme arising from the study shows that service users' subjective sense of recovery is linked with having a greater sense of balance and control to pursue their own personal goals. Thus, McEvoy et al. (2012) conclude that it is necessary to empower service users to identify and pursue important aspects of their lives to facilitate a sense of balance and control in their recovery.

The study by McEvoy et al. (2012) suffers from minor drawbacks. For example, the authors fail to describe how they obtained ethical approval for the study. Also, given that 96 percent of the participants are described as White British, it could be argued that the study failed to reflect on the multicultural diversity and perspectives of service users in Britain, therefore the

findings need to be interpreted with caution. Despite this, the authors demonstrate good sensitivity to context by comprehensively reviewing the relevant literature and linking it to their study. They also show strength by demonstrating their commitment to the mixed method approach through an in-depth explanation of the data collection methods and explicit description of the process of analysis of the emergent themes.

To summarise, the consensus from the literature above is that despite their ongoing experiences with serious mental illnesses, many service users have aspirations to be empowered to make decisions for a better future. However, the drawback of the studies reviewed thus far is that most studies include fewer voices of Black people. The following section describes the synthesis and evaluation of empirical studies on religion and spirituality.

### **3.10.3 Religion and Spirituality**

There is a growing body of literature outlining the importance of religion and spirituality in mental health recovery. One such research is a quantitative study conducted in the USA by Bussema and Bussema (2007) to closely explore the specific roles spirituality and religion play in recovery for people with mental health illnesses. 58 people comprising of one African American, one Hispanic, and 56 non-Hispanic Caucasians attached to a faith-based agency providing psychiatric rehabilitation services completed a spirituality based survey. Statistical analysis reveals that 71 percent of the participants reported that their religious faith and spirituality offered a sense of hope, a positive sense of self, a sense of meaning and an impetus for their recovery. Conversely, the authors report that about half of the participants believed their faith and religious beliefs can exacerbate negative symptoms and interfere with their recovery. Despite this, the authors conclude that the results provide strong evidence that

religion and spirituality can provide incentives for coping and recovery.

A note of caution is due here given that the sample size in the above work is relatively small for a quantitative study. Besides, the authors appear to have used convenience sampling, a non-probability sampling, so the degree to which the sample differed from the entire population is unknown. The authors used a survey, which may be practical and reliable to collect a large amount of information from any number of people, but it consists of restrictive questions that may not necessarily address the experiences of the participants. However, one positive note is that the authors report that the opportunity was given to the participants to provide written comments in five open-ended questions. Yet they concede that these were not included in the analysis, thereby making such provision misleading. The authors also fail to explain how ethical approval for the study was gained. Despite this, Bussema and Bussema (2007) demonstrate sensitivity to context by reviewing the relevant literature on spirituality and recovery and linking this to their study. They also present evidence of reflexivity and acknowledge participant selection bias by the participants' affiliation to a religious-based agency. Moreover, they demonstrate commitment and rigour by providing a detailed description of methods of data collection, analysis and results. The evidence from this study helps us to understand that the spiritual and religious coping experience can be positive as well as negative. In spite of this, the results of the study need to be interpreted with caution because the authors do not ask the participants to identify their religious affiliation, so we do not know what percentage of which religion are identifying religion and spirituality as important.

As part of an ongoing qualitative study of recovery and community integration for people with

lived experience of dual diagnosis in Washington, DC, USA, Whitley (2011) conducted a six-year ethnographic study with about 50 poor African Americans using focus group and participant observation to find out the relationship between religion and recovery. The author found that Christianity dominates the participants' religious affiliation. The participants reported a deeper and intimate relationship with God, and engaging in prayers, reading the bible and listening to evangelical radio, television and music were overwhelmingly reported. Whitley (2011) therefore concludes that service providers could enhance their recovery if they could tap into service users' religious beliefs. The findings are suggestive that people of Black origin overwhelmingly rely on spirituality in their recovery. It remains to be seen whether a similar belief applies to the participants of the present study.

Whitley (2011) demonstrates good sensitivity to context through a comprehensive review of the relevant literature on spirituality and religion. However, he does not make it explicit how ethical approval from the relevant ethics committee was gained. Likewise, the author does not specify how informed consent was gained from the participants. Despite this, the author demonstrates commitment to the ethnographic and qualitative approach through engaging in methodological triangulation of combining data from the focus groups, participant observation, and using an independent person to code the data. The author also seeks respondent validation by discussing the provisional conclusions of the research with the participants. Whitley (2011) demonstrates the association between evidence of research and practice through the discussion of clinical implications of findings. The author specifically emphasises the need to promote recovery by tapping into people's moral resources.

Empirical studies from transcultural and anthropological literature also suggest that many

mental health service users find religion and spirituality important coping strategies for their recovery. For example, Dein and Littlewood (2007) study predominantly White European Pentecostal Christians in London to understand the different ways the congregation receive God's voice. The authors initially administered an introductory questionnaire on prayer to 40 members of the congregation. This was followed by phenomenological interviews with 25 participants who reported in the questionnaire that they heard God's answering voice. Dein and Littlewood (2007) found that 15 out of the 25 reported that they experienced God's voice as coming aloud from outside, and not as part of their thoughts. The participants also reported that they received God's voice in different frequencies and diverse ways. For example, some reported that they received God's voice in dreams and from the scriptures. Others reported that they randomly experienced God's voice on a daily, weekly or monthly basis. The participants felt that God's voice is often pragmatic, comforting and supportive in times of crisis. Thus, there is a likelihood that many Pentecostal Christian church members experiencing a mental health crisis would seek support and comfort from God to help with their recovery.

One of the main weaknesses of the above study is that the authors do not provide any clear statement of the aims of the research. Moreover, recruitment of the participants, methods of collecting data, how ethics approval was secured and issues surrounding informed consent and confidentiality around the participants is not made explicit. Dein and Littlewood (2007) also do not critically examine their own role and potential bias influences in the data collection and participant recruitment. Nonetheless, the authors demonstrate commitment and rigour by sufficiently analysing the data and thus, helping to provide an insight into how

communication with God can enable recovery. However, caution must be applied as the findings might not be applicable to people with different ethnic backgrounds and those who belong to different denominations or religions or none.

In another research, Dein and Cook (2015) use semi-structured interviews to explore the reported experience of communications from God among eight members of a charismatic Christian evangelical Anglican Church in East London. The aim of the authors is to understand how individual congregation members receive communications from God and whether they are indeed from God. The findings reveal that the participants received communications from God through insertion of thoughts and as paranormal experiences. The participants further reported that the communications from God were related to current events and ordinary spheres of life that provided direction, comfort, agency and empowerment in their lives.

Whilst the above research helps us to understand the phenomenological insights about communication with God, Dein and Cook (2015) fail to make explicit the type of qualitative approach they utilise in the study. Important issues such as informed consent and confidentiality relating to the participants are not explained. The authors also do not address potential participant selection bias because the vicar in the research site was given the freedom to select participants for the study. Moreover, whilst the authors describe the research site as representative in ethnic composition and 75 percent of the congregation as non-White, they fail to provide the actual ethnic composition of the participants.

In spite of this, the authors provide a clear statement of the research aim, and also utilise an appropriate qualitative methodology to explore the participants' experiences. The authors

also provide a good explanation of how the participants were selected, the methods of collecting data, and how ethical approval was gained from the relevant ethics committee. Though Dein and Cook (2015) do not provide an in-depth description of the analytic process, they demonstrate sufficient commitment and rigour in data analysis. Moreover, the authors demonstrate good sensitivity to the context through a comprehensive review of the relevant literature on spirituality and religion and relating it to their study.

To summarise, the foregoing has demonstrated the links between religion/spirituality and recovery. Despite insightful outcomes, we know very little about the relevance of religion and spirituality in BASUs recovery. It is hoped therefore that this thesis will address such a knowledge gap. The following section describes the synthesis and evaluation of empirical studies on social support and networks as enablers of recovery.

#### **3.10.4 Social Inclusion**

Studies have identified the importance of social support and networks as stimuli of recovery. For example, Tew et al. (2012) conduct a systematic review of emerging international literature, focusing on the impacts of social factors on recovery. The evolving consensus from the literature shows that relationships with significant others and other social factors have a significantly positive effect on recovery. However, like the systematic reviews described above, the study is a synthesis of already published studies and thus it risks repeating misleading results. Whilst this may be true to some extent, a good systematic review does nonetheless use methods to critique the quality of studies and caution where evidence is weak. Tew et al. (2012) demonstrate strengths transparency by undertaking a thorough and comprehensive search of various databases to identify the appropriate literature on social



aspects of recovery in their review. They particularly demonstrate strength in sensitivity to the cultural context by including four additional research reports when their initial search of the literature reveals relatively few studies on BME experience, community development and self-directed support. Tew et al. (2012) also demonstrate rigour through a thorough and coherent discussion of their emergent themes, as well as in-depth analysis that helps to establish clear insights into the relationship between social factors and recovery.

Schön, Denhov and Topor (2009) utilise a grounded theory study and open-ended interviews to explore the views of 58 Swedish service users with regard to the decisive factors that aided their recovery from mental illness. Findings reveal that most participants cited their sociable personalities, social relationships with professionals, and relations with a network of family and friends as important impetuses in their recovery. The authors conclude that the recovery processes are social in nature and therefore social relationships can play a key role in recovery. Though the authors do not specify how they obtained ethical approval for their study, they demonstrate strengths in context by reviewing the relevant literature and relating it to their study. They also show commitment to the qualitative approach by providing in-depth descriptions of sample selection, recruitment and data collection processes. Moreover, the authors show strength in transparency and validity in data collection process by giving the participants the opportunity to cross-check their own anonymised transcripts. They demonstrate rigour in the data analysis process through a clear and coherent account of their findings that establish an association between social relationships and the recovery process. However, the findings must be interpreted with caution given that the study neglects the diversity and multicultural perspectives of non-White service users.

In a different qualitative study about the social nature of the recovery process, Borg and Davidson (2008) employ a narrative phenomenological approach to elicit the views of 13 service users in Norway and explore how persons with severe mental illnesses experience recovery in the context of their everyday lives. The authors find four areas of everyday life experience – achieving normality, engaging in normal activities, coping strategies in social situations and sense of self-worth – that are important impetuses for recovery. Consequently, Borg and Davidson (2008) conclude that recovery unfolds in the context of everyday life activities. The authors demonstrate good sensitivity to context by reviewing a significant literature on everyday life skills and recovery and relating them to their study. They also show strength in commitment to the qualitative approach by providing detailed and in-depth descriptions of the data collection and analysis of their findings. However, methodologically, the narrative phenomenological approach seeks to understand human experience through the analyses of textual properties and not a person's lived experience. In my opinion, IPA, which is devoted to exploring the subjective lived experiences of individuals (Smith et al., 2009), would have been a more suitable approach. In spite of this, the study contributes to our knowledge by addressing challenges that emerge with mental illness in the context of everyday life.

In another study, Pernice-Duca and Onaga (2009) set out to gather information relating to social networks and the recovery process of individuals participating in psychosocial clubhouses in the USA. The mixed-method study employs a cross-sectional, longitudinal design. The authors conduct two different types of interviews. The first interview comprises 221 participants made up of the following ethnic composition: multiracial 4.5 percent; African

American 10.4 percent; Caucasian 81 percent, and Latino Native American 3.2 percent. The follow up interview was conducted with 179 participants, or 80 percent of the initial participants, 14 months after the first interview, comprising: multiracial 5.0 percent; African American 11.2 percent; Caucasian 81.0 percent; Latino Native American 2.8 percent. The authors find a strong link between social network/interpersonal relationships and recovery and conclude that the importance of understanding the quality of support networks in relation to recovery cannot be under-estimated. However, the study suffers from some minor shortcomings. For example, only 179 participants completed the second interview, which represented a 19 percent attrition rate. In spite of this, the sample size may still be viewed as strong. Pernice-Duca and Onaga (2009) demonstrate good sensitivity to context by reviewing the relevant literature and relating it to their study. They also show commitment and rigour by explaining how ethical approval from the relevant research ethics committee and consent from the participants were gained. The authors provide a comprehensive rationale and objectives for the study in addition to an in-depth description of the research settings, methods of collecting data and the qualitative and quantitative analysis that conveniently complement each other. More significantly, there is a fair representation of ethnic minorities amongst the participants.

Sheridan et al. (2014) conduct a randomised controlled trial (RCT) to establish, implement and evaluate a supported friendship and socialisation programme for individuals experiencing persistent mental illness in local communities in Ireland. The authors evenly allocate participants randomly into either an intervention or control group. No significant differences exist between the control and intervention groups with regards to demographic

characteristics, social functioning, self-esteem, loneliness, depression and social network type. The intervention group is allocated to volunteer for a two-hour weekly social activity (friendships) over a 9-month period, whilst the control group is required to engage in a weekly social/leisure activity on their own. Data from quantitative and semi-structured interviews reveals that the participants' ability to socialise improved because of participating in the study. Sheridan et al. (2014) conclude that supporting people with mental illness to socialise can help to improve their social activities, networks and self-confidence, and reduce the intensity of their symptoms.

Sheridan et al. (2014) demonstrate excellent sensitivity to context through a meticulous review of the relevant literature on social relationships and recovery and linking them to their study. Commitment to RCT is also demonstrated through a detailed, in-depth description of this approach. The authors demonstrate rigour and transparency by providing a detailed description of how they obtained the ethical approval for their study, recruitment process of the sample, qualitative and quantitative data collection process, randomisation process and security and safety of the data. Furthermore, the authors provide a coherent and strong analysis from the data that is manifested in clear themes leading to an innovative insight into recovery as a social process. A key strength of the study is the use of RCT, which remains the gold standard for research. Despite its strengths, the study suffers from some minor weaknesses; for example, the authors fail to specify whether it was a blind study (blind studies usually guide against hidden biases (Greenhalgh, 2014)) and they do not specify the ethnicity and racial composition of the participants.

In summary, the literature indicates that recovery from mental health illness is also a social

process and that forming and maintaining normal and quality social relationships is vital for the person in recovery. However, most of these studies were conducted with very few or no Black African service users. One of the aims of this thesis is to address such a knowledge gap.

### **3.10.5 Medication**

Studies have shown that medication is an important contributory factor in recovery. A qualitative study in Canada by Piat, Sabetti and Bloom (2009) to elicit the views and reflections of 60 service users on the role of medication in recovery reveals five mixed but interrelated views. Whilst 24 participants suggested that recovery is primarily about finding an effective medication, 22 participants perceived recovery to comprise taking medication in combination with other services and supports. 14 participants reported that recovery is about compliance with medication, whilst 11 participants reported that recovery is about having opinions and control with medication. Finally, 20 participants considered that recovery is entirely about living without medication. Consequently, the authors conclude that medication on its own or in combination with other components of care can play an important role in recovery. Piat et al. (2009) stress the need to encourage and support service users to express their opinions and to develop self-management strategies with regard to medication.

The findings of Piat et al. (2009) are suggestive that medication may manifest itself in a wide spectrum for many participants. Many are likely to consider medication in the multi-dimensional domains of clinical, personal and social recovery. Many participants spoke of medication in terms of elimination or reduction of symptoms (Bellack, 2006; Davidson and Roe, 2007; Slade, 2009; Silverstein and Bellack, 2008), or as an ongoing personal process requiring agency, self-determination, empowerment and taking responsibility (Andresen et al.,

2003; Leamy et al., 2011; Onken et al., 2007; Resnick et al., 2004), or in conjunction with others to increase interpersonal relationships and as a source of hope, support and encouragement (Mezzina et al., 2006; Spaniol et al., 2002). It will therefore be interesting to discover the meanings the participants of this project assign to medication.

Piat et al. (2009) demonstrate good sensitivity to context by reviewing the relevant literature and connecting it to their study. They also demonstrate sensitivity to the cultural context by detailing the demographic characteristics of the participants. The procedures for obtaining ethical approval and informed consent for the study are also well specified. Though the type of research methodology is not explicitly stated, there is a good demonstration of commitment and rigour, and transparency and coherence as the authors provide detailed and in-depth descriptions of data collection and analysis, and validation of emergent themes with an independent advisory committee. Piat et al. (2009) demonstrate evidence of research to practice by highlighting how mental health nurses could use their prime position to explore the role medication plays in the recovery journey of service users experiencing severe and enduring mental illness. The study contributes to our understanding of how service users link their recovery to medication.

A qualitative study by Bizub (2013) in the USA, utilising a narrative phenomenological approach to explore a participant's experiences of medication during the acute phase of mental illness reveals that even though the therapeutic benefits of anti-psychotic medication is reported to be positive, the side-effects are debilitating and also exacerbate the already existing sense of disempowerment and alienation. Consequently, Bizub (2013) suggests that collaboration with service users is required to develop an empathetic understanding of their

experiences with medication. A notable weakness in the study is the non-utilisation of in-depth semi-structured interviews to explore the participant's experiences. The author instead elicits a written detailed retrospective account from the participant, thus missing the opportunity for the participant to respond to open-ended questions and talk extensively about his/her experiences and perspective in person (Braun and Clarke, 2013). The author fails to specify the procedures for obtaining ethical approval and informed consent from the participant. Despite this, the qualitative methodology is appropriately used by the author and the study demonstrates good sensitivity to context by reviewing the relevant literature and relating it to the study. Rigour is also demonstrated by providing detailed, in-depth descriptions and interpretations of the participant's experiences.

Studies have raised questions about the consistent and long-term use of anti-psychotics in schizophrenia. For example, Harrow, Jobe and Faull (2014) conduct a longitudinal quantitative follow-up study in the USA with 139 service users with schizophrenia and mood disorder to assess whether many years of treatment with antipsychotic medications can reduce or eliminate psychosis in schizophrenia. The authors assessed the participants prospectively during the acute phase of hospitalisation, and then followed up the participants five to six times over 20-year period through structured and functioning interviews. The authors found that more than 70 percent of patients with schizophrenia who were continuously prescribed antipsychotics experienced psychotic relapse on each follow-up assessment over the 20-year period. The subgroup of service users with schizophrenia who were not prescribed antipsychotic medication experienced significantly less psychotic relapse over the same period. The authors concluded that longitudinally, antipsychotic medications do not always

eliminate or reduce the frequency and severity of psychotic symptoms. The view of the study by Harrow et al. (2014) seems to suggest that not all service users who are suffering from severe and enduring mental illness need medication to recover in the long-term.

A notable weakness of the research is that the authors fail to explain their procedures for obtaining ethical approval and informed consent from the participants. There is also poor sensitivity to the cultural context as the demographic characteristics of the participants are not spelt out. Despite this, the authors demonstrate good sensitivity to context by reviewing the relevant literature and relating it to the study. The authors also demonstrate good commitment and rigour, transparency and coherence by providing detailed, in-depth descriptions of data collection, analysis and validation of emergent themes.

In summary, the foregoing review has shown that recovery from mental health problems is a complex and arduous journey that often requires medication. For some, this is crucial, especially when recovery is considered from the medical or clinical perspective. However, the paradoxical circumstances of long-term and continuous use of medication are also apparent. It will be interesting to find out whether the participants of this study identify with the issues outlined above.

### **3.11 Resilience**

Resilience has been found to be an important recovery component for individuals experiencing mental illness. Like recovery, a broad range of positive emotions and strengths that facilitate people in dealing with adversity have been studied by various authors. For example, in a descriptive phenomenological study to explore the meaning of resilience among



eight Australian adults with experiences of mental illness, Edward, Welch and Charter (2009) found that the participants metaphorically described mental illness as a confrontation with unknown, unfamiliar or unexpected problems in life and thus, it made them feel like being plunged into deep grief and turmoil. However, the participants reported that showing resilience helped them to overcome life obstacles. The participants reported that being resilient was all about establishing human connections and sharing experiences, acceptance, being insightful, having hope and faith, allowing time to heal brokenness, having meaning in life and meaningful relationships, taking charge and moving forward with life. These broad attributions and salient features of resilience are like many of the processes of recovery discussed above.

Edward et al. (2009) demonstrate good sensitivity to context by reviewing the relevant literature and connecting it to their study. The procedures for obtaining ethical approval and informed consent for the study are also well specified. The authors explicitly describe the type of the research methodology used, and there is a good demonstration of commitment and rigour, transparency and coherence as they provide detailed and in-depth descriptions of data collection and analysis. The study adds to our understanding that connectedness can be an important resilience and recovery factor.

In another study in the USA, Deegan (2005) uses a participatory action research to interview 29 people diagnosed with psychiatric disorders to understand how they demonstrate the capacity for resilience in relation to everyday use of psychiatric medication. The findings reveal that participants devoted more attention to personal and non-pharmaceutical medicine when discussing medications. According to Deegan (2005), the participants

discussed personal and non-pharmaceutical medicine in the context of meaning and purpose of life, self-esteem, symptoms reduction and unwanted hospital admissions. Deegan (2005) therefore drew two-point conclusions: 1) that people experiencing psychiatric disorders demonstrate resilience and recovery by means of personal and non-pharmaceutical medicine; and 2) that compliance with medication is likely to improve if clinicians are less interfering and become more familiar with the service users' personal medicine and they use pharmacological interventions to reinforce these self-assessed health resources. Deegan (2005) appears to be postulating that resilience is a crucial factor in determining self-efficacy and positive therapeutic relations with clinicians.

Deegan (2005) demonstrates sensitivity to context by reviewing the relevant literature on resilience and linking that to her study. There is also a clear demonstration of commitment and rigour as the author provides a detailed description of methods of data collection, analysis and results. The evidence from this study also helps us to understand how resilience can help to enhance service user autonomy and good therapeutic relationships.

### **3.12 Summary**

The findings discussed here emphasise the importance of personal recovery for the individual with mental illness. This chapter has also revealed that there is a divergence in the meaning of recovery. Features such as hope, self-control, empowerment, choice, spirituality, social support and networks, medication and resilience were revealed as having a profound effect on personal recovery. However, the evidence from the literature suggests that very little empirical research has been conducted on Black African service users. Moreover, the literature reviewed here confirms that the copious research into the experiences of service

users' recovering from mental illness have utilised qualitative studies and yet despite the prevalence of qualitative studies, there seems to be a lack of IPA studies considering the experiences of BASUs recovering from mental illness. Thus, empirical research is needed to narrow the knowledge gap. The next chapter explicitly attends to theoretical frameworks for addressing the aims of the research and it discusses the detailed epistemological and methodological underpinnings of the thesis.

## **CHAPTER FOUR: METHODOLOGY**

### **4.0 Introduction**

The purpose of this chapter is to address the epistemological and conceptual underpinnings of the research methodology of the thesis. Hitchcock and Hughes (1995) provide an important context for this chapter in their suggestion that ontological assumptions prompt epistemological assumptions, which in turn prompt methodological considerations and then issues about data collection. This chapter begins by positioning the research within an appropriate philosophical assumption; this is followed by epistemological and ontological issues, a discussion of the underlying assumptions of qualitative research methodology and then an introduction of phenomenology as a research methodology. The final part deals with a discussion of the theoretical underpinnings of Interpretative Phenomenological Analysis (IPA).

### **4.1 Positioning the Research within a Philosophical Framework**

This study, which seeks to understand the meanings the participants assign to their experiences of recovery from mental illness, is exploratory in nature. Therefore, the most appropriate research approach for analysing the participants' experiences is a qualitative methodology and phenomenological perspective. As Braun and Clarke (2013) outline, qualitative research puts emphasis on meanings rather than cause and effect. They also argue that the approach captures the complexity, disorderliness and ambiguity of the real world. Braun and Clarke (2013) further argue that the contextualisation and reflexivity embedded in qualitative research allows patterns of meanings to emerge.

There are multiple and diverse epistemological roots for qualitative approaches, but many authors have argued that they converge in the context of how meaning making takes place (Madil, Jordan and Shirley, 2000; Wilig, 2008). Articulating what constitutes knowledge, Takacs (2003) mentions that the adoption of a position can influence epistemology and even the choice of the research topic and design. I took the perspective that my socio-cultural location as a Black African, Ghanaian and a mental health nurse have all shaped my knowledge process and helped me to understand the research questions and findings. For that reason, I will briefly summarise my standpoint.

I was born and raised in Ghana where the predominant culture dictates that the uniqueness of the individual is accepted, but the notion that an individual can be understood separately from his or her social group is rejected (Scheile, 2015). Therefore, my background has strongly preferred a confidence in collectivism and cooperation. I am, for that reason, drawn to the notion that knowledge should be constructed or co-constructed. My epistemological position is influenced by the notion that knowledge should be firmly grounded in social constructionism because I am interested in the interpersonal and social process of how knowledge is generated (Gergen, 1985). I also believe that there are many ways of knowing. Thus, this thesis brings to the surface my own realities as a researcher, the research participants' realities, the realities of the audience and even the mutual realities of the stakeholders in this thesis. Therefore, this research is conducted in the context of how individuals create their own understanding of reality within their social existence (Howitt, 2010). This study is closely aligned to the social constructionist ontology and interpretative epistemology.

## **4.2 Social Constructionist Ontology and Interpretative Epistemology**

In discussing the tenets of the social constructionist movement, Gergen (1985) suggested that the social constructionist inquiry assumes that knowledge is socially constructed through historical, cultural and linguistic domains. Consequently, social constructionists are expected to take a critical stance in understanding the world, as opposed to positivism and empiricism, which prefer all knowledge to be accessed through impartial and unbiased quantitative deductive methods (Burr, 2003; Chalmers, 1999; Willig, 2008). This suggests that social constructionism embraces subjectivity as its core principle. This thesis is exploratory in seeking to understand the experiences of BASUs recovering from mental health illness. It does not seek to test an already pre-defined hypothesis. Thus, my ontological position is that knowledge should be constructed and/or co-constructed with the participants, rather than applying pre-existing hypotheses to generated data. This has also influenced my conviction that knowledge should be firmly grounded in a constructionist and interpretative approach because as Schwandt (2003) points out, constructionists and interpretivists have a common goal of focusing on the process of how meanings are created, negotiated, sustained and modified. Moreover, I am persuaded by Cohen et al.'s (2011) argument that: (1) individuals are unique and not comparable; (2) events are richly affected by context and situations; (3) reality is multi-layered and complex because individuals give multiple interpretations and perspectives to events and situations; and (4) situations need to be examined through the eyes of participants rather than researchers. It seems to me that implicit in these declarations is the point that humans are sense-making creatures and thus it is important to consider their reflections or attempts to make sense of their own experiences (Smith et al., 2009).

Consequently, this thesis seeks to explore the experiences of BASUs in England recovering from mental illness.

### **4.3 Qualitative Research Approach**

This thesis is advocating a qualitative research approach that explores and understands the meanings people assign to their experiences (Creswell, 2014; Hennink, Hutter and Bailey, 2011). There are many different qualitative research methods that typically employ different epistemological underpinnings and analytical strategies (Willig, 2001). Qualitative inquiries seek to shed light on meanings that are less perceptible; they also seek to investigate complexities of our social world. They are inductive and share similarities in exploring ‘what’ ‘why’ and ‘how’ questions, as opposed to ‘how much’ and ‘how many’ questions preferred by quantitative studies. Qualitative research is designed to study people’s life experiences and deliberately shuns quantitative preoccupation with measuring, counting and prediction in favour of describing, exploring, understanding and interpreting a phenomenon (Finlay, 2011). Therefore, the aim of the present study is to use ‘what’ ‘why’ and ‘how’ questions to explore the participants’ experiences of recovery from mental illness, understand key factors that promote their recovery, and to explore the meanings they assign to recovery.

Most qualitative research is guided by concepts from the interpretive paradigm. This means that researchers attempt to study things in their natural settings and endeavour to make sense of, or interpret, the meanings people assign to their experiences in everyday language (Hennink et al., 2011). The uniqueness of the qualitative inquiry is its experiential understanding of the complex interrelationships among phenomena and its direct interpretation of events. Therefore, the emphasis is upon seeking to explore the patterns of

unanticipated and expected relationships in cases or phenomena (Braun and Clarke, 2013; Stake, 1995). Researchers achieve this by exercising their subjective judgement whilst making it clear how their preconceptions shape the knowledge produced through personal reflexivity in a form of self-analysis and self-evaluation during the research (Braun and Clarke, 2013; Willig, 2008).

Qualitative research seeks to understand the personal perspectives of the participants from the participants themselves. It is therefore emic and idiographic. The research questions determine the data-collecting strategies and data is analysed inductively to understand the meanings the participants assign to their experiences. The interpretive nature of the approach enables the researcher to derive insights from the respondents by employing curiosity, open-mindedness, empathy and flexibility, listening to people narrating their stories in their natural settings in order to identify how their experiences and behaviours are shaped by the context of their social, cultural, economic and historical worlds (Finlay, 2011). Qualitative research can be used to explore less known or less understood topics or phenomena to help bring unexpected knowledge to the forefront. The approach is suitable when a detailed in-depth view of a phenomenon is needed to explore a complex process and to illuminate the multifaceted nature of human experience (Creswell, 2013).

Considering all the above, I am convinced that qualitative research is the most suitable approach to answer the present research question because of its holistic method of dealing with everyday human experiences (Finlay, 2011). This thesis is exploratory in nature, seeking to understand the meanings the participants assign to their experiences of recovery from mental illness. A review of the literature revealed that very little has been written about this



topic. Therefore, rather than testing theories or hypotheses to explain the behaviour of the participants, it makes sense to utilise a qualitative approach to explore the participants' experiences. A qualitative approach presents a good story grounded in evidence and meaning (Holloway and Biley, 2011).

#### **4.4 Introducing Phenomenology**

A research methodology that could help to access and explore the lived experiences of BASUs was required. A rigorous review of qualitative research led to the discovery that many contemporary studies in both nursing and other areas of knowledge draw on phenomenology. This is an approach begun by Edmund Husserl and later developed by Martin Heidegger, which seeks to study lived human experiences, as well as the way things are perceived and appear to the consciousness (Finlay, 2011; Henriksson and Friesen, 2012).

Phenomenology evolved into a relatively mature qualitative research methodology during the last decades of the twentieth century largely due to a seismic shift from mainly deductive quantitative research to inductive research. Phenomenology has attracted growing interest in everyday experience in the domain of public and professional practice, including nursing, education, psychology and social work (Henriksson and Friesen, 2012). However, such interest has also contributed to the proliferation of phenomenology with little consensus of what constitutes the methodology. For example, heated debates have ensued about the appropriate ways to undertake phenomenological research (Finlay, 2009). Finlay (2011) has identified two broad phenomenological research categories – descriptive and hermeneutic – which follow the broad philosophical traditions of Husserl and Heidegger respectively.

The general focus of the descriptive phenomenological approach is to examine the essence or structure of experiences in the way they occur to our conscious. Thus, descriptions of the experiences are anchored rigorously to the data without the influence of any external theory. This approach is based on the philosophy of Husserl's phenomenology, which involves the principles of epoché, intentional analysis and eidetic reduction. Put simply, the researcher is required to adopt a phenomenological attitude and bracket or put aside past knowledge or presuppositions. The ideas of the hermeneutic or interpretative approach are a sharp departure from the above; this is based on the principle that reduction is impossible and thus rejects the idea of suspending personal opinions in favour of interpretation of experiences. Thus, research findings in this approach are suffused with philosophical, theoretical, literary and interpretative lenses resulting in an aspect of human experience grounded in unrestricted imagination and metaphorical sensibility. Heidegger, Gadamer, Ricoeur and Levinas are the key figures of this approach (Finlay, 2011; Smith et al., 2009).

Finlay (2011) moves beyond these binary categories and further identifies four contemporary phenomenological approaches which do not easily fit the Husserlian and Heideggerian or the descriptive-hermeneutic divide: lifeworld approaches, first person accounts, reflexive, relational approaches and interpretative phenomenological analysis (IPA).

Lifeworld is a descriptive and/or hermeneutic research approach used to explore how everyday experience shows itself in the life-world of individuals. This approach strives to find the intentional relationship between the conscious, social, perceptual and practical experiences by analysing time, space and the taken-for granted presentation of experience. The key philosophers of this approach are Husserl, Heidegger, Sartre, Merleau-Ponty, Schutz,

van den Berg and two contemporary philosophers: Dahlberg and Ashworth (Finlay, 2011).

In the first-person approach, researchers use their own personal experiences and descriptive or hermeneutic approaches to examine the quality and essences of a phenomenon. The approach is inspired by the ideals of Husserl who believed that access to the world is through consciousness as experienced by the first-person perspective. The first-person approach incorporates concrete narrative descriptions of significant events within theoretical discussion and/or literary flourish; it thereby catapults personal reflection to a detailed and deep analysis level that embellishes experiences (Finlay, 2011).

In reflexive-relational approaches, data and/or meanings are seen to emerge out of the context or dialogue between the researcher and the participant; the participant is regarded as the co-researcher in the embodied dialogical encounter. Researcher reflexivity and researcher-participant (inter-)subjectivity is celebrated. These approaches can be drawn from any of the major philosophers of phenomenology work, but the works of Gadamer, Gendlin, Levinas and Buber are particularly appreciated because of their dialogical and empirical spirit (Finlay, 2011).

As seen from the above, various phenomenological inspired research approaches use different approaches, ranging from pure description to interpretation (Davidsen, 2013). Therefore, I was faced with a challenge in choosing the appropriate method and approach to use. Ultimately, I chose IPA as the preferred methodology to explore the experiences of the participants. However, I do acknowledge that IPA is relatively new to mental health nursing and therefore it is difficult to evaluate its effectiveness as a research approach in this field.

Interpretative Phenomenological Analysis (IPA) was particularly attractive because of its commitment to explore, describe, interpret and situate the participants' sense of their experiences (Larkin, Watts and Clifton, 2006).

#### **4.5 Introducing IPA**

IPA has risen in popularity in many academic disciplines due to its useful methodology in studying the existential and illness experience (Finlay, 2011). IPA's emphasis on the convergence and divergence of experiences, as well as its detailed and nuanced analysis of the lived experience of a small number of participants (Smith et al., 2009), particularly appealed to me. However, several authors have criticised IPA studies for being mostly descriptive and not sufficiently interpretative (Hefferon and Gil-Rodriguez, 2011; Larkin et al., 2006). One possible explanation for this criticism is that IPA is thought to be riddled with ambiguities and lacking in standardisation (Giorgi, 2010). Nonetheless, Smith (2011) rejects these criticisms by drawing attention to the increasingly large quantity of publications that outline theoretical, methodological and philosophical underpinnings of IPA. Careful consideration is taken to interpret the experiences of the participants in this study.

IPA is a qualitative approach and specifically an integrative hermeneutic phenomenology (Finlay, 2011) first proposed by Jonathan Smith (1996) in a paper that argued for an experiential approach in psychology that could equally dialogue with mainstream psychology. Its structured approach and qualitative orientation also seems to appeal to other disciplines in human, social and health care research (Finlay, 2011; Smith et al., 2009). IPA has two primary aims: to look in detail at how someone makes sense of life experience, and to provide a detailed interpretation of the account to understand the experience (Smith et al., 2009).

The following outlines a detailed summary of my understanding of the theoretical foundations of IPA.

#### **4.6 IPA and Phenomenology**

IPA seeks to understand lived experience by integrating the works of four major phenomenological philosophers: Husserl, Heidegger, Merleau-Ponty and Sartre in order to illuminate phenomenology as a singular and pluralist endeavour existing in a continuum (Smith et al., 2009).

One of the striking features of IPA is a detailed and systematic analysis of consciousness. Like Husserl, researchers primarily seek to capture the participants' experiences of a phenomenon by *bracketing* their fore-knowledge (Smith et al., 2009). In order to identify core structures and features of human experience, Husserl encourages the questioning of natural attitudes through phenomenological reflection and warns against things being taken for granted. Husserl believes that this can be achieved by consciously setting aside our previous knowledge and detaching ourselves from prejudices, prior understandings and our own history (Finlay, 2011). Therefore, given that the basis of IPA is the examination *of the thing itself*, a thoughtful focus and careful examination of experience in the way it occurs to the participants, as is proposed by Husserl, is essential (Finlay, 2011; Smith et al., 2009).

The present project is concerned with the examination of the subjective experiences of BASUs recovering from mental health problems, aiming to give them the opportunity to reflect and make sense of their experiences. Thus, I begin my phenomenological journey by considering the Husserlian phenomenological principles of reduction/bracketing.

Husserl's thesis on phenomenology has been criticised by many authors for being too philosophical, conceptual and difficult to decipher (Smith et al., 2009). Moreover, the notion that the ultimate human experience can be examined by setting aside preconceived knowledge has been dismissed as simplistic and unattainable (Spinelli, 2005). Smith et al. (2009) contend that experience is witnessed after the event has already happened; therefore, the pure experience advocated by Husserl is elusive and inaccessible.

IPA has emerged by identifying more strongly with hermeneutic traditions and utilising the works of Heidegger, Merleau-Ponty and Sartre to explore and interpret the personal lived experience of the participants. The works of these philosophers complement each other and collectively contribute to a mature, multi-faceted and holistic phenomenology. For example, Heidegger and Sartre's phenomenologies are focused on existentialism, and Merleau-Ponty's centres on embodiment (Smith et al., 2009). Together, these authors have formulated the argument that we are embedded in the world of language and social relationships and that we cannot escape the historical accuracy of all understanding (Finlay, 2011).

Heidegger suggests the term *Dasein* to represent the unique existence of human beings, or literally *being there in the world* to express the inter-relationship and inter-connectedness of human experience (Finlay, 2011; Spinelli, 2005). Heidegger argues that the primary concern for existential phenomenologists is to investigate and interpret existence as it is humanly experienced (Spinelli, 2005). Therefore, the IPA researcher embarks on studying *Dasein* by immersing him/herself in the world of the participants through a lens of cultural and socio-historical meanings (Moran, 2000). This involves an examination of what Heidegger terms *throw-ness*, in that *Dasein* is thrown into this pre-existing world of people and objects,

language and culture, and cannot be meaningfully detached from it (Smith et al., 2009, p.17). Thus, Heidegger's work invites IPA researchers to ground their stance in the lived world of things, people, relationships and language, and question knowledge outside interpretation because interpretation of people's meaning-making of their experience is fundamental to phenomenological inquiry. His work also prompts IPA researchers to be reflexive in their interpretation in relation to their fore-understanding of the phenomenon being investigated (Smith et al., 2009).

As noted above, Merleau-Ponty focuses much of his work on subjectivity, embodiment and our relationship with the world (Smith et al., 2009). Thus, he links phenomenological descriptions to the human existent as a bodily being or 'body-subject' (Moran and Mooney, 2002). At the core of his philosophy is a protracted argument about the pivotal role perception plays in understanding and engaging with the world (Finlay, 2011). Thus, Merleau-Ponty suggests that humans are unique and different from everything else in the world, and therefore they use their holistic sense to engage with the world. He also argues that empiricism has failed to adequately conceptualise the mechanisms of perception and judgement, and that it is essential to acknowledge human existence in shaping the elementary principles of knowing the world. The main lesson IPA researchers can take from Merleau-Ponty's work is his portrayal of the vital role the body plays in knowing about the world. While it is acknowledged that different phenomenologists place different emphasis on the role of sensation and physiology in relation to the intellectual or rationale domain, the place of the body as an essential element in experience cannot be overlooked (Smith et al., 2009).

Sartre's existential phenomenology is concerned with understanding human existence as opposed to understanding the world. The central issues of Sartre's work also cover human freedom and responsibility and the psychology of human action (Moran and Mooney, 2002). In Sartre's view, human nature is more about becoming than being and therefore there is freedom of choice as well as responsibility for our actions. That said, he acknowledges that certain human complexities require the individual's life, biographical history and the social situation to be taken into consideration (Smith et al., 2009). Sartre's work offers IPA researchers the most comprehensive glimpse of what a phenomenological analysis of human experience should look like in the context of personal and social relationships and moral encounters (Smith et al., 2009).

#### **4.7 IPA and Hermeneutics**

The next major theoretical underpinning of IPA is hermeneutics, which is the art and science of interpretation or finding meaning. Meaning in this context is deemed to be something fluid that is continuously open to new insight, revision, interpretation and reinterpretation (Henriksson and Friesen, 2012; Smith et al., 2009). IPA employs four influential philosophers – Heidegger, Schleiermacher, Ricoeur and Gadamer – to advance the thesis of hermeneutic phenomenology (Smith et al., 2009).

Ricoeur links phenomenology and hermeneutics by explaining that experience and meaning are closely intertwined. Thus, in his view, meaning is indispensable to experience. Hence, for Ricoeur both hermeneutics experience and language are co-emergent. Language is not only used for descriptive purposes, but as an expressive force of experience and experience reveals itself only when it is expressed in poetic, figurative and rhythmic language (Henriksson and



Friesen, 2012). Thus, through interactive and textual interpretation, hermeneutic theorists utilise their subjective expressions to reconstruct original meanings during textual interpretation. Hermeneutic phenomenology therefore embraces the literary and poetic aesthetic application of language that emanates from the process and product of research (Henriksson and Friesen, 2012).

Heidegger illuminates that our being in the world presents us with a fundamental interpretative situation that compels us to ask questions about our world (Henriksson and Friesen, 2012). Thus, IPA believes that Heidegger's concept of *appearance of being* captures the essence of interpretation well. The notion is that there is a phenomenon out there ready to be explored but requiring the detective work of the researcher to bring it to light using his/her prior experience, assumptions or preconceptions to make sense of the experience once it is revealed (Smith et al., 2009).

Significantly, Heidegger and Gadamer believe that all understanding assumes an essential element of presumption and interpretation (Moran and Mooney, 2002). Thus, making sense of the respondents' narratives requires the IPA researcher to engage in close interpretation, but the researcher may not necessarily be conscious of his/her preconceptions beforehand. The complex and dynamic way they unpack the relationship between interpretation and fore-understanding may reveal a more robust and cyclical reflexive bracketing (Smith et al., 2009).

An IPA researcher is also said to engage in 'double hermeneutic', in that the researcher is making sense of the participants' sense making. The researcher assumes a central role in analysis and interpretation of the participants' experiences (Smith et al., 2009). Therefore,

the researcher intuitively seeks to probe the surface meanings by reading between the lines for deeper interpretations (Finlay, 2011). The dynamism of interpretation and reflection resounds excellently with the hermeneutic circle model that deals with the dynamic relationship between the 'part' and the 'whole' at numerous levels for a holistic analytical interpretation. In relation to IPA, the 'part' corresponds to the encounter with the participant in a research project, and the 'whole' to the drawing of knowledge and the experience of the researcher (Smith et al., 2009, p.28). I acknowledge that my identity and experiences as a Sub-Saharan African may potentially bias the interpretation of the participant's experiences, but I believe that by incorporating reflexivity and approaching the interpretation with an open mind and heart in order to explore the experiences of the participants, I will be able to bracket my preconceptions and find meaningful ways to interpret their experiences without imposing my own values (Smith et al., 2009). Chapter eight will expand this into a detailed and completely honest account of how my values have influenced the research process and the findings.

#### **4.8 Idiography**

IPA is also said to be fundamentally idiographic in that it is committed to the detailed analysis of the phenomenon under investigation (Eatough and Smith, 2006). IPA takes great care of each case, offering detailed and nuanced analysis, valuing each case for its own merits before moving to the general cross-case analysis for convergence and divergence between cases (Smith et al., 2009). I carefully follow this idiographic approach throughout the analytic process for a meticulous detailed examination of the convergence and divergence between the participants' experiences.

#### **4.9 Summary**

In this chapter I have located my epistemological position within the interpretative paradigm. I have argued that qualitative research in general and phenomenology specifically offers the most appropriate approach to study people's experiences. I also explicitly identified IPA as the appropriate research methodology to help explore the experiences of the participants. This was followed by a detailed critical discussion of the philosophical foundations of IPA. The next chapter discusses the research methods and design

## **CHAPTER FIVE: METHODS AND DESIGN**

### **5.0 Introduction**

The purpose of this chapter is to provide a detailed step-by-step description of the process of data collection and analysis. It begins with a description of how the interview schedule was produced, followed by a description of service user involvement in the research process, then a detailed description of the study design, including sampling procedure, ethical issues, data collection and the procedures for data analysis.

### **5.1 Interview Schedule**

Smith et al. (2009) recommend the creation of an interview schedule to facilitate comfortable interaction with the participants and to prepare for less engaging participants. To follow this advice, a draft interview schedule was produced that incorporated open, expansive and non-directive questions that aimed to encourage the participants to talk at length. The questions were designed to start with easy to understand questions before they proceeded to more difficult and sensitive topics (Smith et al., 2009; Willig, 2008). To make the interview schedule more appropriate and relevant, the respondents' own terminologies and concepts were incorporated into the prompts and follow-up questions (Willig, 2008). The draft interview schedule was revised following a pilot interview and trial (see section 5.2). The revision largely involved the removal of various questions that were felt by the piloted participants to be ambiguous, directive and repetitive. These changes simplified and significantly condensed the length of the final interview schedule (Appendix 3) to the most suitable questions, prompts and probes addressing the prominent issues of the research question. It has been noted that the self is always embedded in the research process (Holloway and Biley, 2011). My own

assumptions, preconceptions and biases may have influenced the designing of the interview schedule. Thus, as required in IPA research, I showed reflexivity throughout the interview process and showed transparency by setting aside any preconceptions I may have held (Smith et al., 2009). For example, when the participants were narrating their experiences as BASUs in England, I was careful not to project my own feelings onto the interview and say how I would feel if I was a service user. Further, I did not wittingly make overly sympathetic facial expressions when the participants were narrating negative experiences of the services. The significance of this might be that the participants take this as an invitation to elaborate more on these negative experiences than they would otherwise have done.

## **5.2 Service User Involvement**

Collaboration with service users in education programmes and research processes have become a conventional way to add value to outcomes (Kara, 2013; Potter, Murray, and Salmon, 2015). For example, a recent article by Simpson et al. (2014) described collaboration between service users, carers, researchers and practitioners in mental health nursing research at City University, London. Given that this study uses IPA, which seeks to explore the lived experiences of service users recovering from mental illness, it was important to actively involve service users in the research design. Accordingly, the drafted interview schedule was piloted with SUGAR, as well as one volunteer in a pilot interview; these are explained below.

### **5.2.1 SUGAR**

SUGAR is an initiative established in 2009 at City University, London to promote collaborative working in mental health nursing research between service users, carers, researchers and practitioners. The group meets once a month with research staff to collaborate on and discuss

research topics and designs. SUGAR is a true reflection of the rich cultural diversity of London in relation to age, gender, sexuality and ethnicity. It also consists of people with mental and physical illnesses and various degrees of life experiences (Simpson et al., 2014). A draft of the interview schedule was presented to SUGAR in one of their meetings, where members provided valuable comments and suggestions about it. Among the comments received were that some of the questions were 'awkward', 'too academic', 'too technical' and 'too difficult' to understand from their perspective. Some members also commented that some of the questions were too 'leading' and 'repetitive'. This feedback provided insightful ideas for revision of the interview schedule. For example, questions that were highlighted as ambiguous were rephrased and repetitive questions deleted. However, it is recognised that because of cultural differences, the comments and contributions of the non-Black African SUGAR members are likely to provide a context for potential validity issues. For example, Yardley (2000; 2008) notes that reality is multi-layered and different people have competing perspectives that are usually shaped by context, culture and activities. Despite this, comments and feedbacks overwhelmingly contributed to the general improvement of the interview schedule, which was later piloted with a Black African service user.

### **5.2.2 Pilot Interview**

The pilot interview was conducted in December 2010. The pilot interview was motivated by the idea that it helps to refine data collection plans and the conceptual clarification of the research process (Yin, 2009). Given that a small sample size is usually used in IPA research (see section 5.3), one pilot interview was conducted with a BASU who was receiving care from the research site. The participant, Abdul (pseudonym), was recruited through the care

coordinator who verbally introduced him to the researcher. Abdul is a 30-year-old man from Sudan who came to England in 2003 as a refugee; he was given a notice to leave the country after his asylum application was refused. This appears to have triggered his mental health problems. Abdul has had three admissions to psychiatric wards, but he is currently receiving care under the community mental health team. Data from the pilot interview was not used in the main study, but it was formative in helping to draft the final interview schedule and the literature review.

### **5.3 Sampling**

Though it has been argued that there are no hard and fast rules about sample size in IPA (Smith et al., 2009), some authors have argued that the idiographic nature of IPA analysis necessitates a small sample size to provide sufficient comparisons and interpretation without getting overwhelmed by the data (Hefferon and Gil-Rodriguez, 2011; Smith and Osborn, 2003). A review of IPA studies by Brocki and Wearden (2006) shows that the number of participants ranges from one to thirty. Accordingly, twelve participants were purposively selected for this study.

### **5.4 Inclusion and Exclusion Criteria for Participants**

Potential participants were required to be receiving care from the adult mental health services and given a primary diagnosis of mental illness. They were expected to be first or second generation Black Africans, and identify themselves as belonging to the geographical region of Sub-Saharan Africa. As stated above, 'self-concept' (Rosenberg, 1979) is important in determining the inclusion/exclusion criteria; therefore, participants were selected based on their identification with Sub-Saharan Africa, either born and bred there, and/or family

born/bred there. Therefore, other people of Black African descent (e.g. African Caribbeans) who are not from Sub Sahara Africa were excluded from the study. Participants were also required to have the capacity to give informed consent and adequately understand written or verbal information in English language as there was no budget to provide necessary translation of written information and interpretation.

### **5.5 Introduction to the Research Site**

The research site was an NHS Foundation Trust providing specialist mental health and community health services to a population of around 900,000 within the south central region of England. Data was mainly collected in the region's largest town, which has a population of 155,698. According to the 2011 census, 6.7 percent of the town's population described themselves as Black (Office for National Statistics (ONS), 2011). However, compared to different geographical areas, such as London, the Black population in the research site is very small.

### **5.6 Access to the Research Site**

Access to the research site was unproblematic because of the benefit of being employed as a senior mental health practitioner in one of the community teams. Despite this, there was a written agreement with the research and development department that commencement of data collection was subject to gaining favourable ethics opinion from the Local Research Ethics Committee (LREC). A few advantages and disadvantages were associated with being an insider at the research site. I provide a reflective account of this in chapter eight.



## **5.7 Recruitment Process**

The recruitment of the participants involved four approaches. In the first approach, I circulated the research recruitment pack containing the participation information sheet (Appendix 4) and response slip at the reception of the main hospital of the research site; this invited eligible participants to the study via internal mail or by returning the response slip using a researcher addressed envelope or to a designated staff member. In the second approach, I sent emails via the research site's secure network and attached the recruitment pack to clinical staff, advising them about the existence of the study. In the third approach, I arranged informal meetings with staff from both the inpatient and community mental health services for informal discussions about the research project. I took the opportunity during the meetings to ask staff to support the recruitment process by approaching eligible service users and informing them about the research project. Finally, I personally attended the inpatient wards and met with prospective participants face to face to tell them about the research. Before I entered the premises, permission was sought from ward staff to approach prospective participants.

## **5.8 Ethical Issues**

A favourable ethical opinion was granted by the City University Research Senate Committee and a NHS Local Research Ethics Committee (LREC) (Appendix 1). Ethical guidance and safeguarding principles protecting the dignity, rights, safety and wellbeing of the participants was drawn from the 'Research governance framework for health and social care' (Department of Health, 2005b). These safeguarding principles are discussed in the following paragraphs under the following headings: informed consent, confidentiality, due care, right to withdraw

and debriefing.

### **5.8.1 Informed Consent**

Prospective participants were fully informed about the research procedure and their consent to participate in the research was sought (Appendix 3) before they became involved. Prior to the interviews, prospective participants in the community were contacted over the telephone for an initial conversation about the research. Individual meetings were later arranged at convenient times for the prospective participants. Face to face meetings were also arranged on the wards for inpatient service users. These meetings offered opportunities to provide reassurance and to answer any concerns raised in relation to the research. Rubin and Rubin (2012) state that the interviewer gains confidence by taking time to learn something about the interviewee and the research setting. Holloway and Jefferson (2000) refer to this as attempting to achieve equilibrium between the researcher and the participants.

Braun and Clarke (2013) contend that power relations between the researcher and the participants are shaped by the location of the interview. Thus, during the meetings, prospective participants were given the opportunity to choose convenient dates and the place they wished to be interviewed. However, for safety and policy reasons (of the research site), interviews were agreed to be held in inpatient facilities for participants who were receiving inpatient care. The intention of allowing the participants to choose the location of the interviews was to neutralise the sense of power inequalities the participants might be experiencing. Participants were informed verbally, as well as through the research information sheet and consent form, that participation in the research was voluntary and this would not impact on their care.

### **5.8.2 Confidentiality**

Participants' confidentiality was preserved in accordance with the Data Protection Act (1998) and the Nursing and Midwifery Council Standards of Conduct, Performance and Ethics. For example, the code calls on practitioners to: 'Respect people's right to privacy and confidentiality' (NMC, 2015, p.6). Information about the confidentiality of the research was verbally outlined to the participants and in the participant information sheet. Participant anonymity was guaranteed by giving them pseudonyms, which were then used during interview transcription and the entire research process. All data are stored on password protected drives and computers only accessible to the researcher. However, it must be acknowledged that confidentiality and anonymity cannot be wholly ensured when a large amount of personal information is presented. For example, there is the possibility that members of the clinical team will identify some these participants. Crow et al. (2006) argue that it is challenging to disguise the identity of participants without introducing an unacceptably large amount of distortion into the data.

### **5.8.3 Due Care**

Knox and Burkard (2009) have suggested that many participants participate in studies for several positive reasons. Therefore, the aim during the interviews was to build on such goodwill. The sensitive nature of the research topic had the potential to provoke emotions and lead to painful memories and feelings. Hence, the participants' body language was constantly monitored, along with how they answered questions, in order to get an indication of whether they were becoming uncomfortable with the line of questioning. The rationale was to help to reduce or contain any distress to the participants and to explore only the lived

experiences they were comfortable to discuss.

To pre-empt any unforeseen contingencies, participants' care coordinators and/or inpatient staff were also informed on the day of the interview to be alert in case any of the participants become overwhelmed with emotions and needed their support after or during the interview. One of the care coordinators responded to the contingency plan and accompanied me to the participant's home. This proved to be well-judged as the participant became too emotional and distressed and found it difficult talking about her experiences; the interview was stopped 10 minutes 37 seconds into the conversation (a reflexive account of this incident is provided in chapter eight). My experience of caring for service users with difficult sensitive issues was valuable at this juncture. Reassurance was offered and the participant was immediately signposted to the care coordinator (who was waiting in the lobby) for further emotional and professional support. Due to the responsive distress experienced by the participant, the care coordinator was consulted a day after the interview and a decision was made not to re-schedule the interview. The participant was contacted through the care coordinator and she agreed for the data collected from the interview to be included in the study. However, following discussion with my supervisors, a decision was made not to include the data since the interview had not progressed to her innate experiences.

The above incident suggests that the level of disclosure may be influenced by participants' emotions and unease with discussing very sensitive issues in their lives. Since then I have grappled with the difficulties of the situation and wondered if this had a profound effect on how I approached the remainder of the interviews. I have also tried to analyse and evaluate my actions to ascertain whether there were conscious or unconscious hold-backs from asking

further sensitive questions in subsequent interviews. These are important issues that cannot be overlooked as acknowledgement of the researcher's own emotions and that of the participants are important and valuable during data collection and writing up stages (Holloway and Biley, 2011). A detailed reflective account of the research and interviews is discussed in chapter eight.

#### **5.8.4 Debriefing**

All the participants were contacted a day after the interviews for a post interview debrief and in order to provide them with an opportunity to reflect on their experiences in the interview. This also provided the opportunity to ascertain whether they needed signposting to other services for support. No participant expressed any negative experiences about the interviews. They all articulated their appreciation for the opportunity to share their experiences.

#### **5.9 Conducting the Interviews**

Interviews were conducted between December 2011 and May 2012. It has been suggested that a good interviewer-participant relationship inevitably affects participants' self-disclosure and the depth of the experiences they are willing to share (Braun and Clarke, 2013; Knox and Burkard, 2009). Thus, efforts were made to build a good rapport with the participants throughout the interview process. Careful consideration was also given before the commencement of all the interviews. For instance, on the day of the interviews I used my own professional judgment as a mental health nurse to ensure that the participants had the capacity to consent to the interview. All participants were asked to sign a consent form (Appendix 5) to confirm that they were happy to take part in the research. It was also explained to them that they could withdraw from the interview at any time without any

explanation. Each participant also completed a demographic form relating to their gender, age, place of residence, country of birth/origin and religion. This was also a final effort to validate their eligibility before interviews commenced.

Semi-structured interviews were used for data collection. This is typical for IPA studies (Braun and Clarke, 2013; Finlay, 2011; Smith et al., 2009; Willig, 2008). The interview schedule (Appendix 3) was used as guidance throughout the interviews. Interviews were conducted individually in a friendly face to face interaction and recorded onto a digital mini disk recorder. The interviews were conducted in safe, comfortable and convenient environments to reduce any distress to the participants. Six of the interviews were conducted in the hospital premises (in private rooms), and the remaining interviews were conducted in the participants' own homes.

The effect of the location of interviews on data collection has been subjected to a lot of discussion. It has been argued that the meanings attached to the location of an interview can influence the research process (Braun and Clarke, 2013; Elwood and Martin, 2000). For example, it has been found that some service users have negative perceptions of mental health hospital environments (Gilburt, Rose and Slade, 2008). Interviews conducted in the homes of participants are regarded as strategic, aiming to neutralise any supposed power imbalance existing between the researcher and the participants (Braun and Clarke, 2013). This, for example, raises the possibility that the interviews conducted in the hospital premises triggered negative connotations for some of the participants. Equally, it could be argued that homes are not always safe and comfortable places for many service users.

The interviews began by informing the participants about the aim of the research and asking them to openly talk about their personal backgrounds. It then gradually progressed with the researcher requesting that they talk freely about their everyday experiences as service users in England. Follow-up questions with prompts were asked to elicit more information about interesting things they had to say (Smith et al., 2009). The interviews lasted between 35 and 60 minutes. The duration of individual interviews was largely influenced by the participants' eloquence and how quickly they exhausted the narration of experiences.

The overarching priority during the interviews was to find a research identity that would enable effective engagement with the participants and safely navigate their lived experience, enabling them to tell their stories and make sense of their experiences (Smith et al., 2009). Thus, the interviews were approached with ethical negotiation and sensitivity using IPA's qualities of non-judgmental attitude, flexibility, patience, empathy and responsiveness in order to capture the richness and complexity of the participants' meaning making (Finlay, 2011; Eatough and Smith, 2006; Smith et al., 2009). After interviewing thirteen participants in total (one of whom withdrew), it was felt that a sufficient depth and breadth of data about the participants' experiences had been obtained to answer the research question. It was felt that data saturation had been somewhat attained as the narratives by the various participants had become repetitive (Fusch and Ness, 2015).

#### **5.10 Transcription of Interviews**

Smith et al. (2009) recommend researchers do their own transcribing as this allows for full immersion in the data. I followed this advice and personally transcribed all the interviews verbatim. However, rhythmic aspects of the language, such as exact length of pauses and non-

verbal utterances, were not transcribed since the focal aim of IPA is to interpret the meaning of the content (Smith et al., 2009). The complete interview questions, comments and verbal utterances were also transcribed in order to put things into a clearer context (Smith et al., 2009). As stated above, participants' anonymity was guaranteed by giving them pseudonyms during interview transcription and the entire research process. A reflective dairy was kept to record my initial thoughts and comments during transcription and playback of the tapes. This later proved useful during data interpretations.

### **5.11 Data Analysis**

The interview transcripts were analysed manually in accordance with IPA principles (Smith et al., 2009; Willig, 2008). Although data analysis in IPA is regarded as non-prescriptive, it is advisable for researchers to look for shared, as well as unique, idiosyncratic themes across the transcripts (Smith et al., 2009; Willig, 2008). The following stages of data analysis suggested by Smith et al. (2009) and Willig (2008) were meticulously followed for all the transcripts. Three column tables were created for each of the interviews, and each individual interview data were pasted in the middle column. Appendix 7 provides an audit trail of my analysis of the interview with one participant (Jane).

The first stage involved reading and re-reading in order to immerse myself in the original data and to begin the process of entering the participants' world. The aim was to actively focus on the participants and the data and to gain an overall understanding of the structure of the interview, while reflecting on the interview experience with annotations recorded in the left margin of the text to bracket any pre-conceived ideas (Smith et al., 2009; Willig, 2008).

The second stage included initial identification of exploratory themes, which were recorded



in the right margin of the text (Smith et al., 2009; Willig, 2008). This stage involved descriptive comments or phenomenological focus on the participants' thoughts or experiences, with attention to usage of language and metaphors to describe their experiences. This process also included drawing on experiential and professional knowledge and asking a range of questions to find provisional meanings (Smith et al., 2009).

The third stage covered the introduction of structure into the analysis and clustering themes into emergent themes based on their relationships and connections with other sub-themes (Smith et al., 2009; Willig, 2008). This stage involved returning to the transcript with a fresh perspective to check whether new themes would emerge and using the right side of the table to analyse the exploratory/initial notes as emergent themes (Smith et al., 2009).

The fourth stage involved charting or mapping the connections between the emergent themes and clustering and summarising them under structured themes in a table together with relevant quotations and key words (Smith et al., 2009; Willig, 2008).

The fifth stage was about moving to the next transcript and repeating the entire process above. This required bracketing of my preconceived ideas acquired from the previous transcript(s) and treating each case as unique (Smith et al., 2009).

The sixth stage included looking for patterns across cases and integrating them into an inclusive table of superordinate and subordinate themes (see table 3) (Smith et al., 2009; Willig, 2008).

## **5.12 Assessing Validity and Quality**

The quality and validity of this thesis will be assessed against the dimensions of evaluating

qualitative research set by Yardley (2000; 2008): sensitivity to context, commitment and rigour, transparency and coherence, and impact and importance. My discussion is also largely influenced by Smith et al. (2009) who use Yardley's well established criteria to ground validity and quality in IPA research.

#### **5.12.1 Sensitivity to Context**

I show sensitivity to context by offering detailed contextualization in the background chapter that is relevant to the research question. I coherently locate the research within the relevant existing literature (see chapter three) and demonstrate an awareness of the key concepts of IPA, my chosen methodology (see chapter four). In the methodology chapter, I give the rationale for choosing IPA as my research methodology and discuss its epistemological assumptions. I also show sensitivity to context by establishing rapport with the key gate keepers in helping to recruit the participants who otherwise would have been difficult to access. I give in-depth description of ethical issues surrounding the research and demonstrate sensitivity to the socio-cultural context by listening to the participants' perspective and establishing rapport with them.

#### **5.12.2 Commitment and Rigour**

I demonstrate commitment and rigour by thoroughly describing the research method (during recruitment and interviewing of the participants) focusing on rapport, sensitivity, and empathy the key tenets of IPA research. I also demonstrate thorough and systematic idiographic analysis of the emerging themes and demonstrate in-depth interpretation skills supported by verbatim extracts to make sense of the participants' narratives.

### **5.12.3 Transparency and Coherence**

I demonstrate transparent approach to data collection and analysis by giving explicit description of the research process including the selection of the participants, detailed description of the construction of the interview schedule and the interview process. I have aimed to enhance the transparency of my analysis by including an audit trail in Appendix 7. The informed analytic process of the data helps give novel insights into the research topic. I demonstrate coherence by showing that the research question is consistent with the philosophical principles of IPA which is committed to examining how people make sense of their major life experiences (Smith et al., 2009). Moreover, in line with IPA ideals, the presentation and analysis of the findings show commitment of phenomenological and hermeneutic awareness to make sense of the participants' experiences. I demonstrate reflexivity throughout the thesis by honestly declaring how my values have influenced the research process. For example, see chapter eight.

### **5.12.4 Impact and Importance**

This study produces novel insights and understanding of the participants' perspectives of experiences of recovery from mental illness in England. The study also highlights many ways in which the emerging themes could be considered for future development of services for BASUs (see chapter seven).

### **5.12.5 Independent Audit**

Independent audit is another authoritative way to show validity in qualitative work (Smith et al., 2009). I created the opportunity for independent audit by fully documenting and leaving a digital and/or paper-trail of each stage of the research process, including the formulation of

the research question, writing of the research proposal, designing the interview schedule, audio tapes of the interviews, analysis of transcripts, emergent themes, draft reports and the final report. Moreover, my research supervisors acted as independent auditors during the various stages of the research process. For example, my research supervisors audited a selection of interview transcripts and the initial code of the data and thoroughly checked emergent themes to ensure coherence of arguments and whether they were supported by the data.

### **5.13 Summary**

This chapter has presented a detailed description of the methods used in this thesis. The processes of recruiting the participants, ethical considerations, interviewing and analysing the participants' narratives of their experiences were thoroughly discussed. The process of data collection and analysis were presented with constant analysis and evaluation of my own actions as a researcher. The next chapter presents the findings.

## **CHAPTER SIX: FINDINGS**

### **6.0 Introduction**

The analysis of the interview transcripts, as outlined in the previous chapter, led to the findings that are summarised in Table 4 below. In-depth exploration of the superordinate and subordinate themes in Table 4 will form the basis of discussion in this chapter, which is presented in five sections. I acknowledge that the themes discussed in this chapter are only one possible account and do not cover all facets of the participants' subjective experiences. Themes were selected due to their relevance to the research question. There was convergence and divergence between themes, some of which are mentioned in the analysis. Participants were labelled with pseudonyms and verbatim quotes have been lifted directly from the transcripts together with the page and line number from the interview transcripts. This allows the reader to follow the story of each participant, as well as to provide evidence of the claim being made. To increase the coherence of the selected quotes, some have been abbreviated by using three dots (...). These are words like 'erm', 'I mean' and repetition of words or a chunk of text that was felt to impede the reader's understanding (Smith et al., 2009).

### **6.1 Limitations of IPA**

As already articulated in chapter four, the choice of IPA as the preferred research methodology was motivated by its potential in providing interesting and detailed insights into the subjective lived experiences of small number of participants (Smith et al., 2009). However, the methodological limitations of IPA need to be considered.

Wilig (2008) argues that IPA suffers from four major conceptual and practical limitations:

the representational validity of language, the suitability of the participants' accounts, the descriptive nature of the method, and the discordancy between cognition and phenomenology. These are discussed below.

First, employing discursive and discourse analysis theories in articulating her criticism of phenomenology and IPA, Wilig (2008) draws attention to the role of language in phenomenological research which is concerned with understanding actual experience. She argues that language equips people to capture their experiences and can therefore be taken as dictating how reality is constructed. A case in point, the use of language in certain contexts can add unintended meaning to the description of experience (Potter and Wetherall, 1987), therefore, the representational validity of language is arguably, the bedrock of phenomenological research, but many phenomenological studies give unsatisfactory recognition to the integral role of language (Wilig, 2008). In their rebuttal of this criticism, Smith et al. (2009) accept that meaning making takes place in the context of narratives, discourse, metaphors etc., and whilst the primary purposes of IPA is to gain insight into experience, it is always intertwined with language.

Secondly, Wilig (2008) questions whether IPA can accurately capture the experiences, and meanings of experiences rather than opinions of it. She argues that whilst phenomenology as philosophy correlates with introspection allowing the philosopher to explore his or her experiences through 'phenomenological meditation', phenomenology as a research approach relies on the accounts of participants and the experiences of researchers. Yet, the critical unanswered question is whether both the participants and researchers have the requisite communication skills to successfully communicate the nuances of experiences. Moreover,

phenomenological research is suitable with the most eloquent individuals (Wilig, 2008). This may be particularly the case when interviewing people about sensitive issues such as mental illness. But the criticism could be seen as elitist, suggesting only those having access to the right level of fluency are allowed to describe their experiences. As for this thesis, the rich data and analysis presented in this chapter sufficiently demonstrates that this appeared not to be a major concern.

Thirdly, Wilig (2008) argues that the fact that IPA, like other phenomenological inquiries focuses on perceptions is problematic and limiting to our understanding, because phenomenological research seeks to understand the lived experiences but does not explain why they occur. Wilig (2008) argues that an authentic research inquiry seeking to understand the experiences of its participants will also seek to explore the conditions that triggered the experiences which are located in past events, histories or social-cultural domain. But this thesis does not appear to fall into this criticism. As would be seen in this chapter, the rich analysis of the participants' narratives is suggestive that this study is to some extent, an inquiry into the cultural position of the participants using hermeneutic, idiographic and contextual analysis to understand their experiences (Smith et al., 2009).

Finally, Wilig (2008) argues that the assertion that IPA is concerned with cognition exposes it to criticism because first, some aspects of phenomenology are not compatible with cognition and the role of cognition in phenomenology is not properly understood. However, Smith et al (2009) rebuff this by arguing that the IPA's prerequisite of sense-making and meaning-making which encompass formal reflection clearly resonates with cognitive psychology. In summary, there also seem to be a suggestion that even in the presence of solid

philosophical foundation, many IPA studies are still conducted badly as they are more descriptive and not sufficiently interpretative (Brocki and Wearden, 2006; Hefferon and Gil-Rodriguez, 2011). Consequently, active steps are taken in this thesis to give voice to the experiences of the participants, followed by an informed interpretation of their narratives. However, I acknowledge that as a black African and researcher, my biases may impact on the interpretations and results of this study. Moreover, as highlighted in section 4.1 that the findings of this study are constructed and co-constructed with the participants, I also recognise that there are many ways of knowing therefore, the interpretations of the findings in this chapter are just one interpretation; they are partial, emergent, and open to further interpretations. I recognise that other readers may construct different interpretations (Finlay, 2008). IPA is fundamentally a subjective research approach, so two analysts working with the same data may come up with different interpretations (Brocki and Wearden, 2006; Smith et al., 2009). However, for quality assurance purposes, my research supervisors regularly checked and validated sections of my interpretations for coherency.

## **6.2 Introduction to the Participants**

Thirteen people who identified themselves as BASUs initially agreed to participate in this study and offered narratives of their lived experiences of mental illness. However, one female participant withdrew from the interview (see section 5.9.3 for reasons) which left 12 participants who completed the interviews. Pen portraits of the individual 12 participants (three men and nine women) who completed the interviews are presented in Table 4 (All names have been changed to preserve anonymity). Their ages ranged from 19 to 57 and contact with the English mental health services ranged from two to 18 years. Five of the



participants were from Sierra Leone, four from Zimbabwe, two from Ghana and one from Zambia. Four of the participants had a primary diagnosis of paranoid schizophrenia, six had schizophrenia, one organic delusional (schizophrenia-like) disorder, and one had severe depressive episodes with psychotic symptoms. In addition to their primary diagnosis, all three men had struggled with illicit drug and/or alcohol dependency. All the participants had previously received care in inpatient facilities. Admissions ranged from one to several times, and all the participants had been previously detained under the Mental Health Act (1983). All the participants identified themselves as religious and belonging to the Christian faith. At the time of the interviews, four of the participants were receiving care in inpatient facilities – one in a psychiatric rehabilitation ward, and three in acute psychiatric wards. The remaining eight were living on their own, in either the local council or housing association provided accommodation, or privately-rented accommodation.

**Table 4: Pen portraits of the research participants**

<p><b>Ama</b></p> <p>Ama is a 31-year-old woman from Ghana. She has lived in England for the past 10 years, in 2007 she presented with a first episode of psychosis and was subsequently admitted under the Mental Health Act 1983. She has had three previous compulsory admissions. Ama lives with her Ghanaian husband and their two children. She works full time as a check point assistant in a major supermarket. She studied part time in a local college but has given up her studies due to her mental illness and family commitments. She is pregnant and is expecting her third child.</p>
<p><b>Bobby</b></p> <p>Bobby is a 27-year-old man from Zimbabwe. He came to England as refugee with his mother when he was only 15 years old. Bobby was not granted an asylum status for many years, making it difficult for him to attend school or work. He soon succumbed to peer-pressure and began to abuse alcohol and cannabis, and shortly after this began to present with psychotic symptoms, verbal and physical aggression. His mother contacted his GP and the police when he was 19 years old and was subsequently sectioned under the Mental Health Act 1983 for nearly three months. Bobby is unemployed and lives at home with his mother.</p>

He has a care coordinator and a community support worker.

**Asana**

Asana is a 42-year-old single woman who migrated from Zimbabwe as a refugee. She has a diagnosis of schizophrenia and is also HIV positive. Asana has had multiple admissions to acute psychiatric wards due to non-compliance with her anti-retro viral and anti-psychotic medications. Asana's presentation on previous admissions have been characterised by delusional thoughts that she doesn't need to eat or drink because God will look after her. In one of the preceding events to a previous admission, she locked herself in her flat for two weeks and the Police had to force entry. Asana is supported in the community by her care coordinator and community support worker.

**Jane**

Jane is a 29-year-old single mother of two children. She migrated from Sierra Leone as a refugee. She suffered childhood emotional and physical abuse in the hands of her father and step mother. Her traumatic experiences were exacerbated by witnessing a brutal civil war in her native country. Jane started to experience mental health problems shortly after immigrating to England and was subsequently diagnosed with schizophrenia, soon after having her second child. Her problems were compounded by the death of her mother who had parental responsibility and custody of her children. Currently Jane lives in her own flat supported by her maternal uncle and care coordinator from the community mental health team. Jane is unemployed and each of her two children live with her ex-partner and a family member, respectively.

**Eve**

Eve is a 24-year-old woman from Zambia who immigrated to England with her mother more than 10 years ago. She has a diagnosis of schizophrenia and is currently admitted to an inpatient rehab ward. The history of her mental illness is unclear, but it is believed that she started to experience psychotic symptoms soon after she came to this country. Her present admission was as a result of being detained by the police, under section 136 of the of the Mental Health Act 1983 when she was seen wandering on the streets in a confused state of mind. Eve is currently on long-term admission due to housing problems.

**Kofi**

Kofi is a 26-year-old second-generation Ghanaian born in London. He lived in London until the age of seven and then his mother took him to Ghana to live with family members for three years. He was brought back to England and stayed for another two years, and then was taken back to Ghana by her mother for another two years. He has lived in England continuously from the age of 15. He has a diagnosis of unspecified nonorganic psychosis. Kofi described his unsettling childhood, misuse of cannabis, and fractious relations with his parents as the onset of his mental illness. Kofi is currently under the care of the EIP team and supported by a care coordinator.

**Zena**

Zena is a 23-year-old woman from Zambia. She came to England with her father when she was 18 years old. A year after arriving in England, Zena started to experience psychotic

symptoms when she was studying for her A-levels. She was soon sectioned and was formally diagnosed with paranoid schizophrenia. Her mother took her back to Zambia for further psychiatric treatment, but her stay over there was brief, and she soon returned to England. Zena attributes the shock of experiencing new culture as one of the main precipitants to her mental illness. She is currently studying a degree course at a university.

**Mariam**

Mariam is a 44-year-old woman from Sierra Leone with a diagnosis of paranoid schizophrenia. Her mental illness can be traced back to when she lived in another European country in the 1990s. She and her three children migrated to England in 2001 to join her husband, but Mariam is currently separated from her husband. Mariam is currently on admission in an acute psychiatric ward. She was sectioned due to noncompliance of her prescribed medication. One of her children is also a service user. Mariam works as a cleaner but states that she has not been paid since being admitted to hospital, and has been worried about her unpaid rent and bills while on the ward.

**Aisha**

Aisha is a 44-year-old divorced woman from Sierra Leone with a diagnosis of schizophrenia. She immigrated to England in 2001 to join her then husband. Her first contact with the mental health services was in 2007 when she was sectioned for experiencing delusions of being sexually violated by her housemates. Apart from her intermittent delusions, Aisha is able to function well and manages to look after her two children on her own. She also works part time as a cleaner. Aisha travelled to Sierra Leone to try 'traditional medicine' but she returned to England when her delusions intensified. She has a care coordinator and is predominantly managed in the community since her first admission.

**Sheena**

Sheena is a 57-year-old woman from Sierra Leone who immigrated to England in 1992. She currently lives in a two-bedroom council property with her grown-up son and mother. The history of her mental illness is believed to date back from the age of 19. However, her first contact with the mental health services in England was in 1995. Since then she has predominantly been treated for positive symptoms of psychosis, low mood and impaired functioning. Complicating factors in her care have included excessive alcohol use, medication overdoses and problems with engagement. Sheena is classified as vulnerable person so her finances are managed by a third party. She has a care coordinator and is predominantly managed in the community.

**Sheku**

Sheku is a 21-year-old man born in Sierra Leone. He immigrated to England in 2001 together with his mother and sister to join his father who had already settled in England. In 2007, he started to experience first symptoms of psychosis so his GP prescribed antipsychotic medication, but he did not take it. He also refused support from the local mental health services. Shekus's behaviour changed shortly after this. He became increasingly paranoid and started talking to himself. His mother, who is also a service user became worried about his presentation and contacted the mental health services for support. Sheku was

subsequently sectioned. He is currently receiving support in the community from the EIP team.

### **Tina**

Tina is a 35-year-old divorced woman from Zimbabwe. She came to England in 2008 to join her husband, but they divorced after two years. Tina reports that she was bullied by her ex-husband and alleges that he installed surveillance cameras to check her every move. She eventually ran away to a refuge home. But her paranoid beliefs continued in the refuge and was subsequently sectioned and admitted to a psychiatric hospital. Tina has two previous compulsory admissions to acute psychiatric ward. She is a trained as a social worker in Zimbabwe however, she has never worked in this capacity in England.

**Table 5: List of superordinate and subordinate themes**

<b>Superordinate themes</b>	<b>Subordinate themes</b>
It is different in Africa	Why I came to England
	The way they care about them is different' – I am lucky I am here
	They all act crazy, mad, or different
	'Africa is different'
It all started in England	I didn't know it was a mental illness
	This is where the problem started
	Sectioned
Shattered	Sense of underachievement and burden
	'It has got some drastic connotations'
	I was not like this
'Freaked out'	'Black people like to talk a lot'
	'It just completely freaked me out'
	'An adopted-child or a step-child'
	Support from professionals

	Support from family and friends
Focus on recovery	Resourcefulness and self-awareness
	‘There is anointing everywhere’
	Medication
	The meaning of recovery

### **6.3 It is Different in Africa**

A common thread highlighted throughout this superordinate theme is the participants’ desire for a better life in England. Four subordinate themes exploring the participants’ motivation to migrate to England, their perceptions of mental illness and services in their native countries, as well as an exploration of fond reminiscences of life in Africa are discussed in this chapter.

#### **6.3.1 Why I Came to England**

This subordinate theme explores the multiple migration trajectories of the participants. All the participants used the interview to reflect on and describe the experiences leading them to come to England. Participants cited education, family links and displacement from their native countries as the main reasons for coming to England. Whilst myriad reasons were cited by the participants for migrating to England, it appeared that the common motivation was to improve their life.

Several of the participants cited family links as the main reason for coming to England. For example, Mariam a 44-year-old woman from Sierra Leone, reported that she and her children came to England to join her husband who had earlier relocated from another European country. Zena, a 23-year-old woman from Zambia, reported that she came to England with

her father. Zena detailed in her narrative that her family moved several times in her native Zambia due to her father's work before they finally relocated to England:

I come from Zambia...the capital city of Lusaka...I lived there since I was very young. I've lived in Ndola, where...copper is mined...that's where I used to live at first. But we moved to Kabwe, when I was in my third grade up to until the seventh grade, then we moved to Lusaka from when I was in the eighth grade to the twelfth grade then I moved to the UK after my grade twelfth...I was eighteen years old...I came with my dad [Zena 1.2-12].

Zena had a clear sense of her moving from one place to another before eventually settling in England with her father. A more in-depth exploration of her narrative indicates that she came to England at a symbolic time when she was coming of age and transitioning to a young woman. Ceremonies and rituals play a central role in many African cultures for teenage girls transitioning to adulthood, some of which have been condemned as harmful and life threatening (Ssenyonjo, 2007). Thus, we may debate whether this had any significance in the timing of her move to England.

Some participants narrated that they came to England to seek refuge. Collectively, the participants' accounts revealed that they had faced many hardships in life, but they always found a way to be resilient. For instance, Jane, a 29-year-old woman from Sierra Leone, reported that she came to England as a refugee fleeing civil war in her native country:

I came here because I was a refugee back home we had a war. I struggled to come to England. It was difficult, so we had to fight for visas to come to the United Kingdom. So I finally got my visa in Gambia to come to the United Kingdom [Jane 1.9-11].

Similarly, Aisha, a 44-year-old woman from Sierra Leone, also reported that she came to England as a refugee fleeing a civil war in her native country:

I came here because there was a conflict in Sierra Leone so I tried to escape to have a safer life [Aisha 1.15].

Likewise, Asana, a 42-year-old woman from Zimbabwe, reported that she came to England as an asylum seeker:

I came here because I was running away from the political situation in my country...I came here as an asylum seeker [Asana 1.18-24].

For these participants who came to England as refugees or asylum seekers, there seemed to be a different meaning attached to their experiences. They all talked about fleeing violence, civil war and political persecution for a haven in England, and were determined to make a new life that would guarantee access to security, as well as a stable income, shelter, food and reliable healthcare. Interestingly, Jane talked about her 'fight for visas' to come to England. Her description conjures up a powerful sense of the difficult emotional journey involved in getting to England. The fact that she eventually made it to England, her seemingly 'promised land' should have given her ample reasons to rejoice. However, for Jane and many other participants, the initial joy of coming to England soon faded, and the change and improvement they hoped for quickly stalled giving way to mental illness that threatened to hijack their lives and dreams of coming to England. This reading is evident in the narrative of Aisha:

As soon as this started on me, that is the time I knew, maybe this could never change because the voice is three years now and I'm still hearing the voices...I can't do what I want to do. Even...I did some childcare course before they attacked me, I just finished the course then this problem started, I'm not able to go to the work and I paid fees for that...that worries me, it

makes me feel bad...My children are getting big now, there will be a time...I won't be on benefit anymore and so all this is worrying me, if I don't return to work how can I survive? How can I manage my life? All this is worrying me [Aisha 12.344-353]. Here, Aisha is describing her initial reaction to experiencing an auditory hallucination. The feeling of intensity and the sense of hopelessness are suggestive of her fear that mental illness is threatening to take over her life in England. The sense that she will not be able to do the work she has spent time and money training for, and the possibility of losing out financially fuels feelings of intense frustration and fear. I would suggest that by stating 'if I don't return to work how I can survive?' Aisha is perhaps highlighting that mental illness is an existential threat to her whole life, and thus has kindled her inner fears and sense of vulnerability.

Kofi, a 25-year-old man born in London to Ghanaian parents, reported that he lived in both England and Ghana when growing up:

I was born in London...I lived in London until the age of seven and I then went to Ghana for three years, I came back to London and stayed for another two years, went back to Ghana for two years and I have been here ever since [Kofi 1.3-5].

There seems to be a suggestion in Kofi's narrative that he strongly identifies as a second-generation Ghanaian, but his narrative also suggests that he has a deep personal and emotional link with England. At first glance, Kofi's narrative appears to suggest that his parents were encouraging him to experience the indigenous life in their native Ghana. However, he later reflected on the disruption caused by living between Ghana and England:

I think it did have a contribution because throughout my life I had lived here from the age of zero to seven and I suddenly thrown into that culture and be left alone



well in certain circumstances like when my mum decided to re-marry she took me to Ghana and left me there for about three years and I didn't know that my mum was getting re-married and when I came back I learnt that I have a brother and she was married. It was a little bit of a shock to me [Kofi 3.68-84].

Here, Kofi is describing mixed emotions about being sent to Ghana at a very young age. Several points of interest can be noted in his story. First, there is a hint of confusion or perhaps anger when he states that he was 'thrown into that culture and be left alone'. Second, there is a sense of abandonment in his narrative. It could be argued that Kofi was an embarrassment or unwanted by his mother, considering the manner in which she sent him to Ghana and decided to re-marry in England. Third, I would speculate that his mother was experiencing financial hardship and keeping him in England could have continued to cause unbearable suffering to both. Finally, social and cultural necessities may have compelled the decision, as it is socially and culturally congruent for many African parents in England to send their children to their native countries to be in the care of extended family members and learn the native cultures and languages. Whatever the reasons, it is clear from the above extract that Kofi struggled to adapt to changes in his life and this may have contributed to his mental illness. Moreover, I would suggest that Kofi's cocktail of complex experiences invoke feelings of dejection that make it appear that he is stuck in the middle of the worlds of Ghana and England, not fitting in anywhere. I would argue that a life thwarted in this way is more likely to give rise to mental illness.

Kofi's bad experiences do not end here. He also narrated a frightening ordeal of witnessing two armed robberies in Ghana:

Like I had two previous occasions where I had armed robbers come to our house and on both occasions I was the only male of the house so it was quite

frightening...Well, the first time it happened I didn't go outside for a good month or anything; I was nine at the time I think, when it first happened. My grandma got roughed up a little bit so that was a little bit distressing for me to see. And the second time which happened it 2008, that's the one that I kind of remember very vividly because I was asleep and he came and my Mum was upstairs and she was screaming there were just a whole load of things happening. I don't really want to go into too deeply [Kofi 2.58-66].

Kofi's dreadful experience is permanently embedded in his memory; it is apparent from the above narrative that he was overcome with so much emotion that he did not want to talk about it anymore. I would argue that these painful and traumatic experiences have had very real consequences on his personhood, but he keeps a tight grip on these unpleasant experiences, which is more likely to exacerbate any ongoing mental illness. Indeed, Kofi's experiences are distinct from all the other participants. Unlike the rest, he did not choose to immigrate to England, neither did he to go and live in Ghana at a young age by his own volition. It can be concluded that painful feelings of abandonment, adjustment problems and identity loss are reflected in his whole life.

### **6.3.2 'The Way They Care About Them is Different' – I am Lucky I am Here**

The narration of reasons for migrating to England seemed to provide the platform for participants to talk about their perceptions of the state of mental health services in their native countries. Participants presented diverse and multifaceted comparative accounts about the state of mental health services in their native countries and related them to that of England. Even though several explained that they had never received care in their native countries, the theme that the mental health services in Africa are appalling and substandard was recurrent. For example, Asana, who never received care in Zimbabwe, spoke about seemingly cruel and outdated methods of diagnosing mental health problems in the country:

You know Africa is Africa. The way they care about them is different to the way they care over here. Because you know in my country they used to give them like a broken bucket with holes, when they want to see you have a mental health problem and they say go and fetch water by the vegetables; by the flower. If you have got a mental health problem you don't see like there are holes in the bucket. But if you don't...you tell them I can't because there are holes in the bucket [Asana 5.131-136].

Here, by stating that 'the way they care about them is different' Asana appears to be distancing herself from her native country. She also appears to suggest that the predominant diagnostic criteria for mental illness in Zimbabwe are based on assessment of cognitive skills and intellectual abilities and humiliation. If Asana's claim is true, I would suggest that in the context of compassionate mental health care, the services in her native country do not demonstrate empathy, sensitivity, kindness and warmth. However, her statement must be understood with caution as it is important to bear in mind the possible bias it conveys. For example, by stating at the beginning that 'Africa is Africa', Asana appears to be referring to negative stereotypes about the whole continent that is often depicted as one primitive country.

Asana also used an analogy of the first and third worlds to convey the poor state of the mental health system in Zimbabwe when she was asked whether she thinks she would receive different care in her native country.

This is a first world, and you have a third world, you cannot compare first and third world; because we don't get much at these countries. For example, if you talk about HIV we have a problem, and it is common for the rich countries to give us some of their things. It is not easy there; you can't get the same treatment as the rich people [Asana 6.169-177].

Asana consequently spoke about feeling 'lucky' to be in England due to the quality of care she

is receiving as compared to her native Zimbabwe. Her analogy describing the quality of care between the two countries should come as no surprise, but it is certainly useful to look at it closely. Her story possibly tells us something about her internalised embarrassment about her country of birth. She conveys a sense that the mental health services and even HIV care in Zimbabwe are poor. She is HIV positive. When Asana was telling this story, there was a sudden hesitation, and an expression of sadness in her voice and face. There is a sense that she was also conveying an existential threat arising out of suffering from both ailments. It appeared that she was imbuing her lived experiences with meaning and identity, and reflecting on something significant to her. However, as Asana did not discuss her HIV status, I did not ask her how this is impacting her mental health and life in general. The rationale was to preserve her privacy, avoid any distress to her and concentrate on the experiences she was comfortable with discussing.

Asana's reflection of the disparity of care between the rich and poor is poignant but also realistic as it is not possible to genuinely compare the quality of mental health services in Zimbabwe with those of England. As noted above, Asana didn't receive care in her native country, but the quality of care in England may have brought positive changes to her life and she may want the same to happen to service users in her native country. There is also a hint of appreciation of the English mental health system for supporting her recovery journey.

Bobby, who also never received care in his native Zimbabwe, portrayed a cruel, coercive and inadequate mental health system in the country:

Sometimes there is no medication because of the economic situation out there, they mistreat you. When they know you have a mental health problem they

mistreat you, it is horrible, and they beat you up. Out here I am getting appropriate help [Bobby 6-7.276-278].

A similar theme was echoed by Sheku when he was asked about the state of the mental health services in his native Sierra Leone:

Well first of all people cannot afford to buy food; they cannot afford to buy something to eat so how are they going to have that there? There is no medication...They don't really know about mental illness. They know about when you are going mad and you start walking crazy on the street, but they don't really know about mental illness and your day to day thinking abilities [Sheku 4.126-133].

Again, the impression from the narratives of Bobby and Sheku is that poverty and malice are widespread in Africa and there is no quality mental health care prevailing in many African countries. It appears that these participants are expressing a much bigger crisis of confidence in the African mental health services. In their view, African countries have no quality mental health services worth mentioning; therefore, they feel that it is not safe to receive care in Africa. Whilst there may be some truth to their views, it is tempting to present an alternative view. For these participants, emotional connections with their native countries are absent and they also do not wish to be associated with the mental health systems from these countries. Hence, they appear to be using existing negative stereotypes about Africa to further negative stereotypes about the mental health care in their native countries. This point is highlighted by Zena, who received mental health care in her native Zambia. Zena was pleased with the quality of services when asked to comment on the kind of treatment she received in the country:

It was okay, I actually liked it but I was scared at first because there was someone who was more mentally disturbed than I was in the next...room, next door to me

in her room and she used to act all crazy...she used to act all crazy and they would lock her in her room but all the same it was still okay in Zambia, I liked it because we had just TV...I would watch TV, eat breakfast in the morning, my mum used to bring me breakfast lunch and supper, I never used to eat from Zambian mental health hospital either, but they used to cook good food [Zena 4.112-116].

Zena was also explicit that the treatment in Zambia was almost the same as that in England, except that in Zambia you have to pay for your medication and to see a consultant:

In Zambia, you have to pay and you have to also pay to see the consultant and it's very expensive. I paid 8 million for 2 weeks and on top of that I had to pay to see the consultant every once in a month I think. And here, it is free and seeing the consultant is just free as well. They are friendly in Zambia as well, even here they are friendly, but the only difference is paying for your treatment in Zambia [Zena 4.119-123].

Zena described that the inpatient mental health services in Zambia are relatively similar to those of England, especially when it comes to caring staff, treatment regime, food, leisure and visitation rights. However, in sharp contrast to the services in England, she explained how a person has to pay nearly £1,066 to see a consultant (exchange rate of British pound to the Zambian kwacha was 1 to 7,500 at the time of the interview). Zena also stated that service users pay for their own medication in Zambia. Though not all service users in England are entitled to free prescriptions, the fact that many of their counterparts in Zambia are compelled to pay such an exorbitant amount for their care is astounding; £1,066 is likely to be beyond the reach of many ordinary Zambians. Therefore, Zena's narrative presents the impression that good quality mental health services in Zambia are preserved for only the rich.

### **6.3.3 They all Act Crazy, Mad, or Different**

It is interesting that many of the participants used the derogatory words 'crazy', 'mad', 'abnormal' or 'different' in their narratives to either personally describe an individual with

mental illness or how they perceived such individuals to be treated in their native countries.

Such discussion naturally led to this theme. Asana talked about how people with mental illness in Zimbabwe often behave differently in social situations:

Because you can't control them, they do what they want to do; you just let them do what they want...Some of them go into township and they just walk up and down, that shows you that this person is not feeling well and when the music is playing, you see the way they behave from other people, you can tell that this person is different [Asana.6.161-166].

Here, Asana is describing the perceived deviant behaviour of people with mental illnesses in Zimbabwe; as such they are often declared persona non-grata and attract negative comments from the society. Despite this, at least in the context of autonomy, there is a hint that a person with mental illness in Zimbabwe can be seen acting without the usual social constraints and that conformity is not coerced by the society at large. This appears to contradict the negative stereotypes depicted by many participants in the previous section with regard to the mental health services in Africa.

Kofi recounted his negative perception of people with mental illness before he was admitted to an acute psychiatric ward:

All I knew was that people go crazy and that they get locked up in a psychiatric ward and that's it [Kofi 8.239-240].

In this, Kofi conveys the negative stereotype he had of people admitted to a psychiatric ward before he suffered the same fate. This contrasts with his current attitude: he eloquently spoke about the fact that many Black Africans with mental illness face difficulties due to the invisible nature of the ailment:

The only difficulties I face is being African or from an African background; it's difficult for, or I assume it's difficult for, Africans to understand psychosis, depression or any form of mental illness unless it's physical or visible. Otherwise people won't understand so that's a barrier [Kofi 5.149-151].

Kofi offers the plausible explanation that a simple misunderstanding of how mental illness manifests is the main reason why some Africans use derogatory terms to describe the ailment. Moreover, the extracts above illuminate the importance of contextualisation and its meaningful nature in understanding people's experiences of a given phenomenon. As shown in the extracts above, Kofi provided compelling insights into his subjective perception of mental illness in different contexts.

The tendency to embrace derogatory perceptions about mental illness predictably led many of the participants to closely associate the onset of their mental illness with self-deprecatory accounts. For example, Bobby talked about his socially inappropriate behaviour just before he was compulsorily detained under the Mental Health Act 1983:

Physically I would do a lot of things like I would have spasms and stuff. Socially I would not behave appropriately; I would pull my trousers down and stuff like that...my behaviour was sometimes inappropriate, I would sometimes lash out, I would sometimes fight people and stuff like that [1.41-42].

Bobby recognises that he lost his social skills and became aggressive. Although he does not make it explicit that this was because of psychotic symptoms, it is highly probable that Bobby saw himself as 'crazy', 'mad', 'abnormal' or 'different', not fitting into the normal society. Thus, he reflected that being sectioned brought him back to society:

I think it was more like to help me so that I don't harm myself or anyone you know and to bring me back to society [Bobby 1.36-38].

Ama also spoke of her sense of shame in being associated with a mental health hospital



because of the negative connotations of mental health problems:

Sometimes I feel ashamed to go the mental hospital because they think that you are crazy or a mad person; that is what some people think...We Ghanaians don't know what causes mental health problems, because last time when they discharged me one of my neighbours had an argument with me. They said that I was mad because I had been to the hospital so to them I was a mad/crazy person. And I asked the doctor, and he said you are not mad; you are just under a lot of pressure because you are doing too much. Many people think that if you have been to psychiatric hospital you are just mad [Ama 13.369-377].

Ama's sense of shame is in the context of her perception that some people in her community discriminate and disapprove of her use of mental health services. Being called 'crazy or a mad person' evokes self-doubt and anger that prompts Ama to seek reassurance from the 'doctor'. However, it appears that the emotional pain is unbearable for her and this triggers internalised stigmatisation.

All the above suggests that mental health problems are regarded as taboo and stigmatised in many African societies. It is interesting to find out in the ensuing chapters whether the stigma surrounding mental health problems in many African societies has had any impact on the participants' recovery from mental health problems.

#### **6.3.4 'Africa is Different'**

The participants expressed strong sentiments about Africa. As they reflected and reminisced about their native countries, feelings of loneliness, isolation and sadness accompanied such sentiments. There were tensions between difficulties experienced here in England and perceptions, memories, reality and nostalgia for their native countries. For example, Mariam explained why she missed Sierra Leone in the context of loneliness in England:

Here is difficult, in Africa we live a simple life as a family; even your neighbours...are a good family, because when something happens to you they are the first people to look after you before your parents come. When I was in Africa I was good with my neighbours because they are the most important people because when something happens to you they are the first people to attend to you. I remember when I had my daughter in Sierra Leone she was sick and I did not know what to do, I was just crying, my neighbours consoled me and took my daughter to the doctor for treatment. I didn't know what exactly happened I was just sitting crying, and they came consoling me that there is nothing wrong with your daughter so don't cry, if it were to be here, I will die inside and nobody will know it. That is why I say life in Africa is different. Am I making sense? [Mariam 11.324-333].

It is interesting that Mariam invokes this sense of connectedness, peace and harmony she left behind in Sierra Leone. She was noticeably emotional when saying this and the emotion also came across in her voice as well. There was an element of relief in her manner, as if she had not had the chance to speak about her feelings prior to the interview. At the same time, she appeared nervous and uncertain as she recounted her story and asked me if she was 'making sense'. It seemed that Mariam has lost her self-confidence or was still coming to terms with her mental illness and nostalgia about Sierra Leone and the sense of communalism it evokes offered her some hope for recovery.

For Mariam, the communal life in Sierra Leone was a romanticised period of stability and happiness that is still embedded in her memory. She became more animated and continued with her narration by comparing life over there to England in the extract below:

Well, the life here, my brother, is difficult, life here is only work, work...they also work but there is enjoyment in Africa, when we talk of our Christmas, we enjoy Christmas, but Christmas here, everybody is at home, just enjoy it inside the house, (laughs uncontrollably) in Africa our children go out and play with toys, but here children play with guns. In Africa you will not see a child with a knife or gun, where will they get it from? Where will they get the money to buy? It is difficult to see what is happening here in Africa? Though in Africa children fight, but they will not use gun, in Africa we people eat together, I remember my family in Africa

the food is put in a big bowl and we all eat together, so Africa is different from here [11-12.338-347].

Life in Sierra Leone appears pertinent for Mariam and she compares her stressful and demanding life in England to a stress-free and communal life in Sierra Leone. However, she quickly switches the conversation to discuss gun possession in England and Africa. This is a muddled account as she appears to combine her life experience in Sierra Leone with current affairs in England. Mariam was interviewed a few weeks after the riots in several London boroughs, cities and towns across England in 2011. She seemed to be taken aback by the level of chaos she saw on TV and appeared to have concluded that there is moral corruption in England and that such acts could never happen in her native country and Africa. Ironically, there was a civil war in Mariam's native Sierra Leone from 1991-2001 that acquired a reputation for murder, rape, mutilation and recruiting child soldiers (Winter et al., 2016). Despite this, she appears to suggest that there is greater morality and security in Africa than in England. The incongruity in her story may be either due to ignorance or even optimism or patriotism. It could also be that Mariam's unwavering love for her native Sierra Leone invokes a sense of identity, security and belongingness in her. It is peculiar that Mariam referred to me as 'my brother' at the beginning of the section above. Whilst I believe that she was connecting with me as a fellow African helping her to discuss important issues in her life, I also recognise that it could potentially be regarded as over-familiarisation and thus raise some ethical issues about the interview process.

Asana also described how loneliness in England is affecting her and making her feel homesick:

It has affected me in person. You are quiet the whole day... but in my country, you are loud, you chat, you shout.... you laugh, you don't know how the day goes by,

you see. In Africa, you talk to your neighbours, your aunties and uncles...you go there you sit there, you talk [Asana 8.230-233].

Asana found solace in family, friends and community members when she was in Zimbabwe. It also becomes clear further on in Asana's account that she first experienced mental health problems in England, thus suggesting that loneliness may have contributed to her mental illness.

On the contrary, some participants talked about their sociable and helpful neighbours in England. For example, Ama explicitly stated how her neighbours called the ambulance for her when she was unwell and her husband was not at home:

My neighbours called them for me and the ambulance took me to the hospital and they sent me to psychiatric hospital [Ama 2.33-34].

It is unsurprising that not all the participants had sentimental feelings about Africa. Kofi described Ghana as 'a bit strange' when he reflected on his experiences there, whilst Sheku reported that he did not have 'fond memories' when he returned to Sierra Leone. However, it is interesting to note that many of the participants who did not hold any special memories or sentiments about Africa emigrated from there as children and spent most of their formative years in Europe.

### **6.3.5 Summary**

This section has presented an in-depth analysis of the participants' subjective accounts of their migration from Africa their perceptions of mental health systems in their native countries, as well as nostalgic accounts of Africa. At first glance, all the participants had relatively different reasons for coming to England, but the optimism of a better life was the

common thread across their narratives. Judging from this, it would be all too easy to stereotype Africa as a hopeless and impoverished place with civil wars as the hallmark of the continent. However, a corpus of participants were sentimental about the good life they left behind in Africa, although many had negative stereotypes about Africa when discussing their mental health problems. Interestingly, based largely on indirect knowledge or hearsay, participants' descriptions of mental health services in Africa run on a continuum from deprived to admirable. The following section discusses the participants' meaning making of the causes of their mental health problems and events leading to their first contact with the services.

#### **6.4 It all Started in England**

This superordinate theme captures the participants' interpretations of the causes of their mental illnesses and perspectives of the events leading to their first contact with the services. Their experiences are illustrated by three subordinate themes. The first subordinate theme, 'I didn't know it was a mental illness', examines the participants' reflections on events leading to their first contact with the mental health services. The second subordinate theme, 'this is where the problem started', examines the participants' perceptions of the causes of their mental illnesses; and the final subordinate theme, 'sectioned' examines the participants' experiences of detention under the Mental Health Act 1983.

##### **6.4.1 I Didn't Know It Was a Mental Illness**

All the participants used the interview to reflect on their experiences of events leading to eventual diagnosis of mental illness. The participants generally recounted gradual accumulation of strange and bewildering things that they struggled to understand. In all cases

these experiences were entirely new to the participants, suggesting that they lacked a point of reference from which to construct an understanding that it was mental illness they were experiencing. Such an accumulation of experiences was reflected by Asana who reported that she started hearing voices telling her to throw away all her valuable belongings:

The thing is I just threw away everything that I have...everything like clothes, food, from spoon to clothes, yeah; everything in my house...You know the thing it's like, I was having like, I don't know what to call it...someone was telling me to do that, but then I didn't know that it was the mental health problem which I have [Asana 1-2.20-27].

Whilst reflecting on the build-up of her mental illness, Asana portrayed a seemingly contented life after arriving in England as an asylum seeker. She was living independently and had a part-time job as a cleaner. However, the critical moment for her was when she suddenly started hearing voices telling her to throw away all her belongings. It is suggestive from her narrative that her behaviour was unprecedented, yet Asana did not know that it was the onset of mental illness. Asana's struggle to express herself in a coherent manner suggests that she was immersed in a bewildering experience and found it difficult to articulate the way she was feeling. When asked who could be telling her to throw away all her belongings, Asana replied:

I was thinking maybe it was God who was telling me [Asana 3.77].

Different interpretations can be inferred from this statement. First, it is plausible that Asana is deeply religious and is expressing that her experience is a spiritual conversation with God or supernatural beings. This is significant because the ability to communicate with God or supernatural beings is culturally powerful for many Africans, allowing them to show their spirituality or close personal connection with God and/or supernatural beings (Mbiti, 1990;

Turaki, 2006). An alternative interpretation, I would suggest, albeit cautiously, is that Asana is expressing a belief that mental illness is something that could be inflicted by God or supernatural beings. If either of the above interpretations is true then I would suggest that Asana retained a significant interconnection between her spiritual and/or cultural beliefs and mental illness. Asana's experiences are consistent with the suggestion that many Africans believe that they are at the mercy of benevolent or malevolent impersonal powers (Mbiti, 1990; Turaki, 2006). However, it could be argued from a professional perspective that Asana was probably experiencing delusions because of mental illness and lacked the insight to understand her experiences.

Tina also spoke about the onset of her mental illness in the context of events after divorcing her Zimbabwean husband. She reported that she moved from her matrimonial home in a northern English city to a town in the south shortly after the divorce. Soon after this she started hearing voices of people speaking in a Zimbabwean accent. Though she was not specific about whether she heard her ex-husband's voice amongst them, she was 'confused and baffled' by the voices, yet she did not think that her experiences were related to mental illness at that time:

I was consistently hearing voices so it was a continuation of hearing around about seven or more voices. And these were people that had a Zimbabwean accent so I kind of identified them with people from home...My understanding was that I don't know what they are doing. I was very confused and baffled about what they were doing...It was just basically talking, and later it was something that became physical because I could hear them and feel them tapping on my throat and also just my body tapping on my body parts [Tina 1.11-22].

Auditory and tactile hallucinations are common symptoms in schizophrenia. Here Tina is talking about her experience of hearing voices in a very personal and matter of fact manner.

Her experience escalates to frustration as she struggles to understand what is happening to her. Interestingly, she identifies the voices as people from Zimbabwe, suggesting that she felt that the voices and the 'body tapping' were sabotage by an as yet unseen familiar accent. Tina potentially perceived her experience as mere physical discomfort being perpetrated by unseen adversaries and therefore she did not consider her experience to be the onset of mental illness. Tina's experience highlights the complex matrix of social and cultural beliefs that impact upon the development of mental illness.

Hearing voices of people with Zimbabwean accents leads Tina to construct an experience immersed in agonising distress and confusion to the extent that she feels that the boundaries between herself and others have been violated:

It made me very uncomfortable and it made me depressed and distressed...Because the things that were happening. I had never experienced these things in my life so they were things that were very worrying and I also worried about my security...If someone could do this to me then they had an access to my thoughts, brain and they were able to speak into your brain. It is very confusing...It was shocking really but simply because they were people from Zimbabwe and I figured they will be found out by the law so whatever they were trying to do or prove, I don't know what it was, and up until now I am still confused [Tina 1-2. 24-35].

The extract above highlights the level of fear and invasion Tina feels, believing that people can access her 'brain and thoughts'. Despite talking about feeling 'depressed and distressed', she does not acknowledge these to be symptoms of mental illness. It appears that she uses these words to only describe her life or the lived experience of being overwhelmed. Instead, her experience drives her to think about her own security. Her reasons for feeling threatened are acceptable and to be expected because it is normal to feel threatened in the face of adversity. However, a possible reading to be drawn from her narrative is that Tina appears to



fit her experiences to the common Black African perception that the world is filled with affliction and wickedness (Turaki, 2006).

Similarly, Aisha described that her first symptoms of mental illness were experienced as physical symptoms, but she did not appear to understand that as a mental illness:

There was Polish men I was sharing house with and they tried to evil me...They tried to evil me. They fight me...to kill me...and then they were doing that on and on and on...I became sick then I saw the doctors...they referred me...and then I was admitted for a couple of months...But when I got back home, they started on me again. They started evil me, they tried to kill me...So my tummy started getting big...as if I'm swelling [Aisha 1.28-44].

Aisha is a single mother of two young children who previously lived in a shared house with Polish men. It is unclear and difficult to know what happened between Aisha and her housemates; however, her feelings are strong enough for her to claim that all her seemingly unusual experiences and beliefs originated from her Polish housemates. This evidently frightened her and contributed to her deteriorating mental state, and subsequent detention under the Mental Health Act (1983) for two months. Aisha's narrative suggests that she has linked her social and cultural backgrounds with her experiences and associated the origin of her mental illness with evil spirits. There is also a perception in her narrative that her experiences are something inflicted by her enemies or are a malicious human act. The unpleasant physical experience intensified for Aisha and she continues to think that the Polish men are abusing, raping and even trying to kill her through witchcraft:

I just say that maybe it's just an abuse because they rape me through the witch...Yeah through the evil, when they try to kill me, they try to rape me...Yeah it's not physical rape but I do feel it. Just like I'm sitting here, they will be in on top of me. I knew that something was going on. It does affect me; I feel that something is going on... I asked them 'why are you doing this to me?' they said that they

wanted to kill me ... I said 'why do you want to kill me?' they said 'Nothing. We just want to kill you' [Aisha 6.163-177].

Aisha's distress in narrating the above was palpable. The fear in her face and voice when she was speaking was remarkable, and in my view touching. Aisha's narrative of bodily experience of physical abuse is potent and the intensity of her unpleasant experience indicates the level of trauma that she has experienced. However, her experience can be interpreted in another way based on her personal background. Not long before the interview, Aisha was divorced from her Sierra Leonean husband and there were allegations that she suffered physical and sexual assaults from her ex-husband. Though these were not explored with her and it is not clear whether she has reported the abuse to the police, or whether she had received therapy for this, there is a possibility that the abuse she suffered is related to her delusional beliefs. Aisha's personal history of being an alleged victim of physical and sexual assaults, and reported experiences of being a victim of physical and sexual abuse on a supernatural level had potentially had a significant impact on her personality. Easteal and McCormond-Plummer (2006) have found several short- and long-term psychological and emotional effects associated with sexual assault. Like Tina above, Aisha's experiences could also be explained in the context of her cultural beliefs that are apt to attribute critical events to witchcraft or evil spiritual powers (Turaki, 2006), or this could also be a result of the 'Western' medical psychiatry explanation of delusional thinking.

In summary, the narratives of the participants present contextual and powerful complex experiences of what it means to experience mental health problems for the first time.

#### **6.4.2 This is Where the Problem Started**

Admission to a mental health hospital provided the opportunity for the participants to reflect on what they perceived to be the cause of their mental health problems. Their accounts reflect a range of reasons, including immigration and adjustment problems, substance misuse, relationship problems, financial problems, evil spirits, trauma and bereavement.

At least five participants said that problems with their migration status contributed to their mental health problems. This is evidenced by Bobby when he says:

Things like my immigration status...I was just depressed and was just taking it out on people...Basically I would go and sign on I think every month. I used to go...and sign on. I wasn't allowed to work or any of that stuff it was waiting for them to decide what to do whether they would approve for me to stay in this country or not, it was really depressing. I used to travel there, I didn't even work which was really frustrating. I didn't have money to travel and I would have to depend on my mum. Yea and my condition was not really that good at that point...and end up getting lost but it wasn't a good experience getting lost and hearing voices and all that stuff you know. My physical condition was not well; I used to follow what I was thinking and end up somewhere else and doing inappropriate things...I just gave up on myself you know, I just gave up, I had no hope of at all of things, the amount of the immigration thing went on for was quite a while and I couldn't really understand why they wouldn't give me a stay here and stuff like that, why they wouldn't consider me [Bobby 2.58-79].

Here, Bobby is describing his frustration with the protracted immigration problems which he sees as a major stress in his daily life, and therefore this frames his experience in the context of painful feelings associated with the handling of his asylum and/or resident permit application. His narrative suggests that he finds the long-drawn-out indecision about his migration status unacceptable, yet he feels helpless to do anything about it. The restriction imposed on him provokes intense feelings of loss of autonomy and opportunities. In this context, Bobby's lived experiences are arguably defined by feelings of both desperation and

impotency. There are also feelings of disillusionment, anger and aggression, which are directed outwards towards innocent people. It is therefore foreseeable that such experiences would obstruct the development of a healthy sense of self. Though Bobby's story indicates an undercurrent of resentment, this seems to be directed towards the civic and political systems such as immigration officials, the police and employment officials, as opposed to the English mental health system. His experience is suffused with a strong sense of bitterness towards the authorities for mishandling his residence/asylum application. Bobby talked about how the protracted immigration problems triggered suicidal thoughts:

One time I ended up at the river in those days when there was flooding. I felt like jumping in there. It was scary...actually. I left the house to buy a kebab and ended up just following my mind and physically I felt my legs were just pulling me somewhere else and stuff like that and I ended up at the river until one of my mum's friends saw me and convinced me to go home...Mum and Dad were worried about me. It was a Saturday evening when I left and I came back Sunday evening so I did not sleep at all. I had been walking around the river back and forth...It was not a good experience [Bobby 3.115-122].

However, in the midst of all these negativities, he buoyantly reports that he has been partially granted 'discretionary leave to remain in the country':

I actually got discretionary leave to remain in the country, which unfortunately ends at the end of this year and I have to apply again. I couldn't go to college or work when my immigration status was messed up. But I managed to go to college last year, I can do things like work. I can work [Bobby 2.81-84].

The extract above is a defining memory in Bobby's migration to England. The positive impact of being granted a conditional stay in England means that he has become more positive about the present, but his future remains uncertain, as the discretionary leave to remain in the country is temporary. Therefore, for Bobby, his experience is one of uncertainty. On the other hand, it could be argued that this is as good as it gets for Bobby as his protracted immigration

problems seem to have taken their toll on him and have already contributed to his mental illness. Similarly, Ama blamed her mental illness on her migration to England:

Sometimes you feel bad like you ask yourself why? Back at home I did not have this problem and when I came here and all of a sudden something happens to me. I ask myself why, why God? Why, God this happened to me, it's a bit sad [Ama 5.123-125].

Ama's narrative presents a conflicting account of what caused her mental illness; by stating that 'back at home I did not have this problem and when I came here and all of a sudden something happens to me' she appears to suggest that she would not suffer from mental illness if she had not come to England. Yet, she also appears to blame and question God as well when she says: 'I ask myself why, why God? Why, God this happened to me?' Perhaps she feels singled out or that she is being punished by God for allowing such misfortune to happen to her. It could also be suggested that she feels that God is abandoning her. Her account is expressive of a sense of punishment and/or abandonment, which prompts her to become angry at God. Her story is suggestive that spirituality plays an integral role in her life, but anger, blame, abandonment and regret prominently permeate her experiences.

Similarly, Zena blamed migration and adjustment problems for her mental illness:

I think if I didn't come here, I wouldn't have been diagnosed with schizophrenia...because I had to be in a new environment, I had to cope with new races, because in Zambia there are only Indians and Blacks, rarely you find White people but when I came here it's like all races are here so I had to learn how to talk to different races. I had to learn how to communicate with other races as well [Zena 5-6.168-183].

Zena's narrative attributing the cause of her mental illness is somewhat complex and requires unravelling. It appears that she is citing migration, environmental changes and interaction

with different racial and ethnic groups as the causes of her mental illness. Furthermore, it is discernible from her narrative that she was not comfortable moving beyond her comfort zone when she arrived in England. Zena struggled to adapt to the multicultural and multiracial English society. Hence, her exposure to different racial and ethnic groups triggered an adverse psychological reaction that had a detrimental effect on her mental health. Zena's narrative highlights her naivety, as she seems to suggest that she did not expect to find White people in England. Zena also attributed her mental illness to the stress of school work:

I was very stressed about a lot of things, especially school as well because it was becoming too much for me and A-levels was too much for me even though I was only taking three A-levels and I ended up hearing voices telling me to shave my head because I had demons in my head. I started thinking there were demons in everything, I became very confused, I was thinking of going to live in the woods on my own but my mum was thinking that something wasn't right so she called the mental health team and they came to get me [Zena 1.25-30].

The above extract indicates that her mental health further deteriorated with the added stress of studying for her A-levels. Moreover, Zena's narrative demonstrates her belief that her mental illness is caused by demons. Her account is suffused with culturally significant meaning when she says 'I was thinking of going to live in the woods on my own'. Zena poignantly described her experiences of hearing commanding voices:

They are able tell me what to do. There will be times when I don't know what to do, sometimes I will stop talking to my mum, stop communicating with the world or my parents, my family, my friends, so I'm stuck, I don't know what to do, meaning if I'm hearing voices, they will tell me what to do, they will say I can watch TV today or this person is talking about you or this person hates you so don't talk to this person, maybe go to the cinema but my mum wouldn't allow me to go out my own so most of the time I will just watch TV or maybe I'd fantasise that there are people in the room, maybe celebrities [Zena 5.124-148].

It might be possible to suggest that Zena finds the voices harmless and therefore feels obliged

to comply with every command issued to her. However, a closer examination of her account reveals that she feels torn apart by hearing such demonic, torturous and emotionally blackmailing voices telling her to isolate herself from significant others. Zena explained that finding her way through this state of mind proved challenging and thus, as already discussed in the previous section, she dropped out of school for a period and spent months in Zambia receiving treatment.

Bobby reported that he indulged in excessive alcohol and illicit drug use due to immigration problems:

I wasn't occupied, which led me to do things which were bad you know; drug misuse, I used to drink, I used to do all those things which was not good for my health especially when I was experiencing psychosis and hearing voices, it really wasn't good [Bobby 2.89-92].

As outlined above, not being given a legal migration status meant that Bobby was not allowed to work or study. Thus, he appears to have made a personal choice to indulge in drugs and alcohol, which, by his own admission, exacerbated his psychotic symptoms. Likewise, Sheku and Kofi reflected that they developed mental illness after smoking cannabis:

I became unwell when I smoked my last cannabis really yea that's when I became a bit erratic acting a bit violent in a way, say like what was going on in my head like thoughts like it was becoming too much [Sheku 2.41-45].

That was just like smoking cannabis at the age of 16 onwards...it increased my anxiety, while initially I was using it as means to sleep and to get away from things and also to fit in [Kofi 2.35-4].

Although, unlike Bobby, Sheku and Kofi were not facing immigration problems, both frankly admit that smoking cannabis contributed to their mental illness. However, Kofi's assertion that he smoked cannabis 'to fit in' is worth examining in detail. There is a suggestion in his

narrative that he succumbed to pressure from his peers due to a desire to be accepted socially. As explored above, and as will be further evidenced in the next extract, Kofi's lived experiences are defined by abandonment and rejection by his family; therefore, it may have made sense for him to conform to his peers in exchange for their love. However, Kofi was to suffer severe consequences for his cannabis use and he was eventually expelled from the house by his parents for 'not following rules':

Having then been kicked out of the house at the age of 17, a lot of things were negative about life at that time...Well my parents said I was misbehaving or just not following rules and which eventually lead to my step-dad kicking me out of the house [Kofi 1-2.27-32].

Though Kofi was not directly asked what 'not following rules' means, in the context of his entire story, I would speculate that it has something to do with his cannabis use. I would imagine that his parents found his cannabis use and early signs of mental illness to be against the family values, an embarrassment to the family, or challenging behaviour they had no explanation for, so the convenient solution was to eject him from the family house. I would also speculate that Kofi's parents threw him out because they were angry at him for using cannabis and to protect themselves, either from the difficulties he might cause or from embarrassment. Kofi's experiences highlight the issue of stigma, which has been mentioned by some participants in the previous sections, and will be discussed further below, as having negative effects on their mental health problems. His experiences also highlight the culture clash between the Black African youth culture in England and the expectations of their parents.

One participant attributed her mental illness to a difficult pregnancy and traumatic childbirth:



I first became unwell when I had my first baby...When I had Nick (not real name) the birth was caesarean. So I went into coma that's when I started experiencing problems. Well since the pregnancy, I started experiencing um...I'm not feeling well, and my head is not steady. I became unwell [Jane 1.17-19].

At first glance, it is possible to suggest that being a Black African does not make any difference to Jane's narrative above. However, a closer look at her socio-cultural background in the following paragraphs will help to illuminate her experience much better. Her narrative illustrates the link between a traumatic childbirth and mental illness. I would suggest that by stating that 'I'm not feeling well, and my head is not steady', Jane is indicating the experiences of stress and emotional instability during the pregnancy that eventually led her to become 'unwell'. Moreover, Jane describes experiencing suicidal thoughts when she was pregnant:

When I was pregnant, I had this experience, suicidal and wanting to kill myself. Because I miss my family back home so I wanted to kill myself...my body was not in the right home...I wasn't feeling well [Jane 2.33-35].

In this Jane is making a direct reference to the way in which her pregnancy compounded her isolation, nostalgic feelings and suicidal thoughts. Her story is poignant. Though it has been found that it is relatively common for women to experience depression and feel suicidal during pregnancy (Bennet et al., 2004), her account is also suggestive that she wished her family (her mother, father or grandparents) were around at that important and scary time. Pregnancy is said to have a cathartic effect on most African women because it brings joy and hope to the family; expectant mothers are showered with blessings, support and extra attention to make them feel special (Ayisi, 1997). However, Jane's narrative was suffused with ambivalent feelings towards her family as she talked about the trauma she experienced at the hands of her father and step-mother whilst she was in Sierra Leone:

When I was in Sierra Leone, I was...disciplined by my dad and step-mother...I was controlled by them [Jane 2.37-38].

There is a suggestion in the account above that she suffered emotional abuse by her parents when she was in her native country. Her problems were compounded when her mother died in England shortly after joining her:

My mum died...Yeah it has affected me because I miss her. I don't know someone like her. I miss her in the community, I miss her a lot [Jane 4.97-104].

Jane's experience in both Sierra Leone and England has therefore been a two-fold blow. She experiences trauma not only from physical and/or psychological abuse, but also through bereavement. Her experience is touching. She had no close family member around that could offer support during her pregnancy. Her difficult experiences with pregnancy predictably led to her first admission post-partum:

I came in contact when I had my first baby. I came in contact because when I had my first baby there was depression, so I was feeling depressed, I wasn't feeling well. They said it was depression when I came into mental health hospital. I wasn't taking part in activities or associating with friends like I used to. I didn't think it was a mental problem, I didn't think it was that because I was just lying down not having anything to do, not going to work. Because I was not going to work, I was not doing activities...I was just lying down not doing anything and this was not down to mental health problem. Obviously, I didn't think it was down to mental health problem I was thinking that was having depression because I was having my first baby [Jane 2.45-53].

It appears from the extract above that Jane's lived experiences post-partum were dominated by social withdrawal, apathy, inactivity and severe depression that eventually lead to her admission to hospital. However, her statement that 'I wasn't taking part in activities or associating with friends like I used to' contradicts the notion of loneliness or complete isolation discussed above.

### 6.4.3 Sectioned

Many of the participants talked about their eventual admission to acute psychiatric wards under a section of the Mental Health Act 1983 following escalation of their bewildering experiences. Being 'sectioned' triggered an overpowering mixture of painful feelings and negative emotions such as shock, anger, confusion, fear, sadness, worry, a sense of disempowerment and fear of abandonment by love ones. For example, Tina described her shock at being sectioned after she went to the police and the emergency department to confide that she was hearing voices:

When I went to the police I explained the situation to them and they said there is nothing we can do. And I say why because I didn't understand why they couldn't do anything because we are in a free country why not investigate? So then they decided that we are going to have you assessed by a psychiatrist and the nursing team and that's basically what they went ahead and did...I started off on section two and then I was put on section three [Tina 3-4.91-99].

Tina was visibly angry and disappointed as she recounted her experiences. The way in which she talked about her experiences of being sectioned suggests a feeling of resentment towards the police and the mental health team that coordinated her sectioning. There is a sense of loss of confidence in the services as she could not comprehend why she was sectioned for experiences that she believed were real and intimidating. Tina reflected on her resentment at being sectioned and struggled to understand why people would do that to her:

It is very hard, it's extremely hard. Sometimes it's as almost unimaginable, I can't imagine people doing this but you end up feeling quite powerless over the decisions that people make [Tina 4.106-108].

Tina was noticeably emotional and exasperated when narrating her story. She seemed to be recounting feelings of anger and disempowerment and questioned how her civil liberties

could be so violated in modern-day England. Conversely, it could be argued from a mental health professional perspective that Tina is in denial, not accepting that she is experiencing a mental illness and therefore she unreasonably blames the assessment team for colluding to section her. Tina's story suggests that being sectioned can be a distressing life experience that can trigger negative emotions. However, the raw emotions, anger and disappointment that Tina portrayed in her overall narrative of being sectioned is also suggestive that her cultural background as a Black African encouraged her reaction. As a Black African, I too am familiar with the hard, strong and raw expression of emotions in many African cultures when people are not satisfied with events in their lives.

The irony of Tina's reaction at being sectioned is evident when she describes that as a former social worker in Zimbabwe she would in fact be the one detaining people under the country's mental health law:

In an actual fact we would be the ones who would give care there, so if you're a social worker you will be the one who will be sectioning people not the other way around, that you're the one who is getting sectioned [Tina 8.243-245].

Tina is baffled that the tables have turned on her. She is frustrated at being sectioned and is feeling powerless. There is also a suggestion that she finds the power dynamics between the clinicians and herself to be difficult to handle, and this undoubtedly impacted upon her already negative emotions and experiences.

Similarly, Asana narrated a distressing account of how she was sectioned following her assessment at the local emergency department after throwing away all her valuable belongings:

I went to...hospital and then the mental health team came and interviewed me and then took me to the hospital...I was sectioned...I think it was section two or three. I had to stay in hospital for 28 days...I was not happy because I didn't know anything about the condition of the mental health section, so I was not happy. I fought with the nurses...Why are they giving me this section? [Asana 2.38-55].

Being sectioned seemed to provide Asana with the opportunity to reflect on her experience of the whole process. Three possible interpretations can be drawn from Asana's narrative. First, there is a hint in her account that she was not properly informed about the procedures and implications of detention under the Mental Health Act 1983. Undoubtedly, not being fully informed about such a life-changing event would be distressing and alienating. Asana did what many people do in times of adversity – she fought back. It could also be suggested that Asana struggled to accept the reasons given for her compulsory detention. Perhaps Asana found the label of compulsory detention, the thought of her freedom being taken away, and the prospect of submitting to staff demands, difficult and painful to accept, and thus, she decided to fight with the staff. Third, there is a possibility that Asana found her compulsory detention contradictory to her personal and cultural understandings and therefore struggled to integrate these differences in her situation. For a multitude of different reasons, the loss of freedom was a painful and devastating life event for Asana, as it is for most people.

Bobby also narrated his reaction to being sectioned when his behaviour became erratic, seemingly triggered by psychosis:

I actually thought the police were against me sort of thing because they actually sectioned me, I was sectioned by the police and doctors...well they sectioned me...I actually thought that my mum was against me as well you know. She was worried about my condition and alerted the police and doctors you know. I think she was really worried about me. I eventually understood why after I was sectioned...How life was, I was just living on the edge, anything could have happened, anything could have happened. I was a danger to myself you know. I

acted on the stuff, the voices I heard in my head and stuff, sometimes I was suicidal, I thought there was a purpose behind it [Bobby 3.102-113].

It seems that spending time in hospital and receiving treatment brought about behavioural shifts in how Bobby thinks about the police, clinical staff and his mother. His account is evocative of retrospective insight into his problems and appears to acknowledge that all the people who instigated his admission to hospital were in fact acting in his best interest. Bobby further reflected on the experience of being sectioned in the following extract:

It was strange but I thought it was a phase I was going through I didn't really understand it. I didn't really know about schizophrenia and hearing voices at that point until I got sectioned and it was explained to me. I went deep into it and they told me about the whole thing and understood it very well [Bobby 1.46-49].

It appears that Bobby's response to being discharged is expressed as a continuum: at one end of the spectrum he expresses a deep sense of anger and paranoia at the people he thinks are colluding to get him sectioned, whilst at the other end of the spectrum he frames his experience of being sectioned in positive ways, perceiving that the long-term benefits are educating and liberating.

#### **6.4.4 Summary**

This section has presented detailed analysis of the participants' meaning making of the causes of their mental health problems that eventually led to their contact with the services. Many participants appeared to blame migration to England as a contributing cause to their mental illness. The analysis revealed that at the onset of the mental illness, many had great difficulty articulating and understanding what was happening to them. There was vagueness and confusion in their accounts. Although most realised that there was something wrong with

them, they lacked the awareness to acknowledge that they were suffering from mental health problems. From their accounts, they only acknowledged that it was mental health problems they were experiencing after being admitted to hospital, usually under the Mental Health Act 1983. Many derived the meaning of their mental health problems from a web of complex and wider socio-cultural contexts, and being sectioned provoked a deep sense of alienation and disempowerment. In the following section, a detailed analysis of the superordinate theme 'shattered' explores the shared personal experiences of the participants' sense-making of their mental health problems in England.

## **6.5 Shattered**

This superordinate theme explores the participants' sense of devastation arising from their mental illness. The common thread stemming from this superordinate theme is the perceived negative experiences the participants incurred due to their mental illness. This consists of four subordinate themes. The first theme explores the participants' sense of underachievement owing to mental health illness; this is then followed by the second theme, which discusses the connotative meanings the participants assign to mental illness; and the third theme looks at the participants' perceptions of the effects of mental illness on their personalities. The final subordinate theme examines the participants' perceptions of how their own African community members behave towards them.

### **6.5.1 Sense of Underachievement and Being a Burden**

In making sense of their experiences with mental illnesses, many of the participants felt that they had underachieved in life and fallen short in their personal goals. This triggered feelings of frustration and disappointment in their narratives. For example, Kofi constructed his sense

of underachievement in the context of the expectations his parents had for him:

Just to achieve because you know in our background parents expect certain aspirations and certain targets to be achieved or what they want their children to achieve and I hadn't met those...By not having achieved anything meaningful in my life at a certain age and having to go to university quite late, at the age of 21 [Kofi 1.17-23].

Kofi's narrative of what his parents were expecting is vague, but the message that he was expected to reach certain milestone at certain points in his life is clear. A few possible interpretations could be inferred from his narrative. First, by stating that his parents were expecting 'certain aspirations and certain targets' from him, there is a suggestion that Kofi's parents were well-intentioned and wished him to do well in life and that is why they demanded outstanding achievement, whether academic or extracurricular. If that is the case, then I would suggest that Kofi has undergone enormous parental pressure and this may have impacted his self-esteem. Studies have depicted parental involvement as a double-edged sword. For example, Hill and Tyson (2009) find that strong achievement and self-esteem in early adolescence is positively correlated with parental support and negatively correlated with parental coercion. Second, I would suggest that failure to meet the 'targets' set by his parents triggered estrangement from them. Kofi's account suggests that he is longing for his parents' affection. Finally, Kofi's ambition in life is evoked when he states that he had not achieved anything 'meaningful' at a relatively young age. Perhaps he dreamt of success in life, but mental illness has taken away his ambitions and sense of purpose. This reading is strengthened when he describes his entry to university at the age of 21 as 'quite negative'. Here, Kofi is perhaps highlighting his potential as a gifted and determined person with the ability to achieve in life. He is perhaps regretting that he has squandered his talents. Nonetheless, I would argue,



albeit cautiously, that Kofi's expectations in life are unrealistic, possibly due to lack of talent, but he lacks insight into this shortcoming.

Some participants expressed their sense of underachievement through their failures to do something tangible for their love ones. For example, Bobby expressed his frustration about being unable to do things for his mother:

When I look at my situation...I end up just feeling depressed about what I haven't achieved. Where I stand in my life you know, um as well as my mum's condition I feel really depressed and stuff and I worry about her a lot and it is depressing me. I mean when I look at people in my family my cousins and stuff and see how they are standing on their own two feet and what they've done for their mothers and stuff it really gets me down. I am wishing that I could even buy my mum a house and stuff like that, that's my main goal; instead of her having to pay rent and stuff like that...it gets me really down, I feel like I am underachieving [Bobby 6.251-259].

Here, Bobby is comparing his achievements with those of his cousins, which can be read in a number of different ways. First, whilst Bobby highlights his sense of duty to his mother, there is a suggestion in the account that he sees himself as either inadequate or a failure because he has been unable to match his cousins' achievements. Second, I would argue that Bobby's sense of underachievement also unwittingly exposes him as lacking self-awareness, as he does not seem to acknowledge that he lacks the occupational skills to be successfully employed and earn sufficient wages to look after himself and his mother. Finally, his account suggests that he is using his cousins' accomplishments as a litmus test to evaluate his own success in life.

Some participants' narratives also reflected that they have become a burden to others because of their mental illness. For example, Mariam spoke about how her mental illness is affecting her daughter's university education:

It has affected my daughter because she is in university and since I was brought to the hospital she is not been feeling good, she is having problems about it...she said she can't concentrate on what she is doing...Well, I am not happy but it what can I do, there is nothing I can do. I am only praying to God to help me, it is the only thing I believe...Yeah with my daughter, she said she is worried because I have been in the hospital, and she can't concentrate in what she is learning [Mariam 7.203-212].

Here, Mariam's mental illness is felt as a double blow. Not only does she experience the negative consequences of the hospital admission, but her daughter also experiences consequences. Mariam's experience is one of sadness, helplessness and a sense of being a burden. The role of mother and daughter has changed or reversed: in many cultures, it is the mother's role to emotionally support her daughter, but in Mariam's case the reverse is true. Furthermore, there are three possible readings of her commitment to prayers and God in her narrative. First, she is highlighting a deep conviction that God will somehow resolve all her problems; second, this could be indicative that she does not take an active role in her own recovery; and third, it could be that she does not believe in conventional clinical interventions and is solely putting her faith in supernatural intervention.

Similarly, Aisha narrated how her mental illness is affecting her children:

I don't see my children...my (ex)-partner takes care of them, and they started crying, they want to come back to me...They started crying, they want to come back to me. So I do feel all of this...it makes me feel bad [Aisha 11.296-307].

Here, Aisha is narrating her experience in the context of her children's reaction to her being unwell and the children having to go and live with her ex-partner. Her account describes how an emotional and physical distance is created between her and her children whenever she becomes unwell. I would suggest that her experience is affecting her ability to fulfil her role

as a mother in this regard.

### **6.5.2 'It Has Got Some Drastic Connotations'**

Many of the participants used the interview to reflect on how their mental illnesses were impacting on their life opportunities; for example, in describing the negative consequences of her diagnosis, Tina says:

Obviously being someone that wants to go back to work, connotations are that you have got a mental health problem and you might not be able to do some kind of jobs. So it has got some drastic connotations and also socially, it's like oh she's schizophrenic...there are implications, obviously...it has got limitations on what you can do in future, it even have a bearing that is in marital status and things along those lines. So it has got a bearing on a lot of things, being locked up in a mental institution has got a bearing on a lot of things...Because now you become quite limited in regards with what it is that you can do. Being a new country to me, I am not sure exactly what those limitations would be but I do know that in my field there will be limitations [Tina 5.132-147].

Tina's account highlights her concerns that experiences of mental illness are alienating. She talks about the stigma she feels in relation to her diagnosis with schizophrenia and how this could potentially affect her personal life. She further laments that she might not be able to get a husband because of her mental illness and is therefore imagining a harrowing and lonely future. There is evidence that Tina's account is influenced by social and cultural expectations. For example, Ezeobele et al. (2010), and Patel (1995) have suggested that fear of genetically transmitted mental illness has compelled many African families to conduct investigations before sanctioning marriages. Furthermore, on a professional level, Tina feels that she will be constrained with regard to opportunities. It is interesting to note the way in which she introduces the idea that she is in a foreign country and therefore she is unsure of how her mental illness will affect her career. Tina is a qualified social worker. A probable interpretation

is that, for Tina, her lived experiences are defined by fear of alienation and insecurity in a foreign country.

Likewise, fear of abandonment was reflected in Aisha's account:

When I'm not feeling better so maybe he will try to leave me...He will not cope with me...because of this same illness my partner left me...If I have another partner after that they will leave me because of that. I will not feel good [Aisha 10.281-291].

Here, Aisha appears to recount her heartache about her ex-partner leaving her because of her mental illness. In the extract above, the insecurity about a similar thing happening to her again seems very real. She is hinting that she may never have a partner in her life because of her mental illness. Moreover, I would speculate that her account is laden with negative social and cultural implications, because some African societies consider women who are not married at a certain age to be immoral and they are often shunned and isolated. Aisha might be worried about suffering such a fate. In many African cultures marriage is regarded as the moral fabric that can bring stability to the entire community – living and non-living things (Mbiti, 1990). Her narrative suggests that her lived experience is suffused with low self-esteem, sadness, insecurity, fear of rejection and fear of stigma.

Some participants suggested that their mental illnesses were causing irrational behaviours and decisions that had negative ramifications. For example, Asana talked about how she threw away her work permit, which consequently made it difficult for her to get a job:

It has affected me in many ways. I even threw away my work permit...So it's like I cannot even get a part-time job; I didn't have any work permit. So it is not easy, sometimes when you find a part-time job and they say bring your permit. And you don't have a work permit, what are you going to do? It is like pushing me back to

square one...It's like I am going a step backwards. Maybe I can look for a part-time job. Like for two hours cleaning or four hours but you don't have work permit but you really want to do that job, you really want it, to help you and to keep active. It is better than staying at home all day, two hours or four hours cleaning. You go there, you socialise with other people from different countries and it is much better than just staying at home the whole day [Asana 6-7.182-193].

There is a sense from Asana's account that her mental illness was the impetus for irrational behaviours and/or decisions when she describes how she threw away her work permit and thus suffered the consequences of not being able to secure work. Her account also suggests that an internal tussle is taking place for her as she dwells on the missed opportunities in her life. Her sense of frustration at missed opportunities is evident when she says 'it's like I am going a step backwards'. I would suggest that her reason for making that statement is twofold: she rues both the missed opportunity for successful employment and the missed opportunity to socialise with others. Her account also indicates that she has insight into what could enhance her recovery journey.

Despite the perceived negative connotations of mental illness raised by many of the participants, others reported that they had actually experienced positive things in their lives despite their ongoing experiences with symptoms. Beneficiaries of financial or material support from the government, non-governmental organisations and institutions were appreciative of the kindness and generosity given to them because they helped to boost their recovery journeys. For example, Zena and Kofi talked about some of the positive things they have gained from their mental illnesses:

I'm able to get benefits like disability living allowance (DLA) and government support allowance. In university I'm able to get extra time when I'm taking exams. I'm able to have extra support with the disability services in school. They are able to give me study skills, have one-to-one sessions with a tutor who would help me

understand questions...Yeah, and I'm able to talk to an adviser who is assuring me that everything is going to be okay [Zena 9.261-268].

I've paid off my debt, that's one positive thing. I am a lot more aware of mental health and I am currently living in supported housing and that's a positive thing because I don't have to worry about my housing for the mean time. And I suppose my finances are ok and my health has improved a lot [Kofi 7.201-204].

Financial, emotional and psychological support from the university seem to provide Zena with the opportunity to construct her experience with mental illness in a positive light. She talked about how the support is inspiring and motivating her to continue with her university course. There was a suggestion in her account that she would have dropped out of university if such supports were not available to her. Zena's experience is evocative of the fact that the right support can make a difference in the lives of individuals with mental illness and help them to function to their fullest capacity.

For Kofi, it seems that experiences with mental illness have translated into financial help and a place he can call home. He talked about how he had become financially independent and less reliant on others. Kofi sounded relieved when he was saying this, as if a weight had been taken off his shoulders. Kofi also hinted that he was on the road to recovery because of the support he had received and his sense of liberation was clearly evidenced in his account.

There were opposing views presented about the gains that come with mental illness. A few participants, for example, felt that they can be damaging. Sheku captured this well:

The only thing I can say that has been helpful, beneficial in my mental illness is the ESA and DLA apart from that nothing else has ever been helpful...Yes it is helpful for person like me but it is damaging if you lack motivation. So I know I am going to be dependent upon that for quite a long time, you see so it is quite damaging to me. Getting that amount of money does disable you to motivate yourself to go and look for something to do [Sheku 10.346-353].

Sheku's narrative in the extract above gives a whole new meaning to receiving mental health related benefits. He sees mental health-related benefits as both a blessing and a curse. For him, the biggest negative is that it incapacitates and demotivates the beneficiary and takes away the incentive to find something meaningful to do. Thus, Sheku is suggesting that it is challenging for him to hone the skills needed to function in the real world. Despite this, the irony of his situation is apparent when he says 'I am going to be dependent upon that for quite a long time'. My suggestion in this regard is that he appears to have accepted this situation and will continue to be dependent on hand-outs for a very long time, a gloomy self-assessment indeed. Moreover, I would suggest that he is in a state of dissonance due to his inconsistent attitude towards benefits.

### **6.5.3 I Was Not Like This**

The idea that mental illnesses are impacting on the participants' physical appearance and behaviour was reflected in their narratives. Many talked about how mental illness had affected their self-image. Others felt that they would not be able to enjoy things they used to enjoy because of their diagnosis. For example, Jane talked about how she had gained weight and lost interest in many important things in her life:

I was well. I was fit. I was size eight, going out, going clubbing, going shopping, and going raving. I was doing all these things. But when I first became weak, I was not doing all these things. That's why people were concerned and saying that I was depressed because I'm the one that goes out, doing things, having fun, raving, and doing all these things because I'm not doing things, all the community get shocked because I'm not going out, I'm not having fun so people are getting worried, 'why isn't this bubbly girl not having fun? She used to have fun; she used to get down on the floor. Why is she not having fun now?' And so people worry, that's why I'm in here [Jane 5.143-150].

The way in which Jane describes changes in her physical appearance – in terms of her dress

size, behaviours and the way people react to her – suggests a feeling of self-resentment. It appears that such a feeling has triggered gradual withdrawal from her social circles and she has eventually alienated herself from the community. The discussion of changes in her appearance and behaviours led Jane to poignantly reflect on her general outlook on life:

The way I used to party, I will not party anymore. The way I used to complete tasks, I will not be able to fulfil tasks...My family will not see me in the same way...At first I wasn't mentally disturbed, now I am mentally disturbed they will not see me the same way. The way I have changed. The way I talk has changed. They will not see me in the same way. Everything has changed [Jane 6.166-174].

Here, there is a sense of despair and relinquishment taking place for Jane. Her story is moving because she gives the impression that her mental illness is stealing her personhood and identity. For Jane to state that 'my family will not see me in the same way' is suggestive of her impression that she is being alienated from her family because of her mental illness. The notion that a self-confident and fun-loving person like Jane would give up having fun because of experiences with mental illness, even becoming alienated from her own family, must be an unpleasant experience for her.

Aisha also talked about how changes in her physical appearance are making her feel ashamed of herself:

The way I look like, I don't like it because I was not like this before. I was not with big tummy, I was not fat but since I've got this problem I became fat, I have big tummy, I don't even like it because some people that knew me before, if they saw me they ask me 'are you pregnant?' so I don't feel good...I feel bad. I don't feel good at all...I do hate myself because the way I look [Aisha12.323-328].

It seems that for Aisha, her self-consciousness about her appearance triggers an intense feeling of shame. Aisha uses 'they' to refer to people from her own community. Many of us



can perhaps recall how negative comments from friends about our appearance can stir up negative feelings or emotions, but remarkably Aisha does not allow this to have a lasting devastating effect on her and she attempts to tackle her body-shame with a healthy lifestyle:

Well I was doing some exercise, I was going to the gym to lose some weight but I didn't see any improvement. I went to the gym for three months, twice a week, I do go but I don't see I am losing weight...I decided to stop going to the gym [Aisha 12.333-337].

Nonetheless, Aisha finds the limited results of her healthy lifestyle discouraging and there is a sense of frustration and failure in the extract above. Likewise, many of us can recall similar incidents of failure or failing at something we needed badly in our lives at that time dampening our spirits. In most cases, we get the opportunity to pick up the pieces, come back stronger and have another go. However, in Aisha's story, there is a hint that she finds the results of the healthy lifestyle counterproductive and discouraging, to the point of abandoning her quest for good. Sadly, Aisha has yielded to the power of failure and this will perhaps have consequences for her recovery journey.

#### **6.5.4 'Black People Like to Talk a Lot'**

The final subordinate theme in this section examines the participants' perceptions of how their own African community members behave towards them. The themes that emerged as common across all the participants' narratives in this regard were gossip, stigma, negative reactions and alienation. For some, the gossip about mental illness in their communities was something they struggled to comprehend. Sheku explained that he found the excessive talking about people with 'mental illness' among the 'Black people' difficult to accept:

The thing is...Black people like to talk a lot. When he sees that person has a mental illness that person might start talking, talking, talking. It doesn't really affect me in a way because I don't think about those things really, but it might affect my Mum because she might be affected about this. But I have a very good understanding about the way things are...It is the way we are programmed, you cannot change that...we haven't really understood what mental illness is about so it is not really common for them. It is most African people I can say that about. When they hear you have a mental illness they think you are walking in the street mad. But they don't quite really understand how it affects different people in different ways, so they think when someone has mental illness it is some sort of demonisation. You may think you are less of a person in this world [Sheku 9.284-296].

The extract above speaks volumes about Sheku's feelings of bitterness towards the 'Black people' he perceives as always 'talking', gossiping and stigmatising those with mental illness. It is important to undertake a detailed examination of his account. First, he explicitly states that because of his 'good understandings about the way things are' he is not bothered about the gossips, but he goes on to explain that his mother (who is also a service user), might be affected by the gossip. I would argue that Sheku is tacitly worried about the gossip and his unease is hidden behind concern for his mother. Second, Sheku appears to suggest that he has insight into his mental illness when he says he has 'a very good understanding about the way things are'. Third, he reflects an understanding of mental illness in religious terms when he says 'when someone has mental illness it is some sort of demonisation'. Fourth, Sheku appears to suggest that 'Black people' are 'programmed' or predestined to gossip about people with mental illness; this suggests that it is perhaps socially and culturally acceptable in many African cultures to treat people with mental illness negatively. Interestingly, Sheku perceives White British people to be understanding and empathetic towards persons with mental illness:

I used to go to a...church and most of the people there were (White) British. I had this close friend...she has been ill since she was 20 and she still hasn't recovered...but the one thing they do have is understanding, they do understand that if a person is unwell it does not mean that they are less of a person [Sheku 9.297-304].

Sheku's account is a scathing indictment of the African community's prejudiced treatment of people with mental illness. There is also a perceptible sense that he is disappointed and distrustful of the African communities for their attitudes towards people with mental illness.

Sheku therefore stated that he has disengaged and isolated himself:

For me personally it affects the way I interact with people in general. I don't really get personal like ask questions about other people; I tend to isolate myself in a way. I don't ask too many questions all I do is like stay in my room thinking about stuff and getting a better understanding about things and I just keep alone [Sheku 9.309-313].

Sheku's narrative indicates that he has consciously chosen to emotionally and physically detach himself from the African community at large. He feels that, as far as his recovery journey is concerned, negative experiences with the African community are too toxic to associate himself with. He thinks that it is in his best interest to protect himself and isolation is the best answer. However, Sheku was unable to predict that this choice to isolate himself from his own peers and community would be detrimental. In the extract below, Sheku narrates how his social skills have deteriorated:

My head itself doesn't enable me to do things like be more closer with people and my friends. When I am walking in town with my friends it is like they are talking about different things but I would keep my mouth shut and just keep walking really. And they may be bragging about girls, bragging about trainers or bragging about going clubbing but that does not seem to interest me to be honest [Sheku 10.330-334].

There is a sense from the above extract that apprehension and low self-esteem have hijacked

Sheku's sense of self. It appears that he feels socially awkward and he is not enjoying life at an age where, all things being equal, things like girlfriends, clubbing and fashion should interest him. His present outlook on life is suggestive that his whole life is submerged in the strangeness of mental illness and the consequence is apathy; his peers are living experiences that he does not have or share – another loss.

Some participants were overwhelmed by the negative reactions from their community. For example, Kofi spoke about how the negative stereotypes and the worry that he would not be accepted by others instigated his isolation from his friends:

I was worried about that, the acceptance from other people because that led to me having lots of friends that I have before but I just decided not to engage with them anymore because I just felt that if I was unwell there was a stigma attached with it. There are a lot of friends that I have that just don't even know [Kofi 5.153-156].

Here, Kofi is suggesting that excessive worries and fear of being stigmatised by his own peers were daunting and his natural response was to immediately withdraw from his social group in expectation of being ostracised. Jane and Mariam also reflected on how gossip within their communities is affecting them:

They gossip 'you have mental health problems', and that's a bad tag on my name [Jane 8.236-237].

Sometimes when you have a problem and discuss with other people though they wouldn't help you but will spread it to others that is why when I have a problem it is not everybody that I tell I have a problem [Mariam 10.289-291].

There are suggestions from the accounts of Jane and Mariam that being gossiped about by the people from their own communities is extremely frustrating for them. Therefore, Mariam responds to this and makes a conscious decision to talk to a selected and trusted few about

her mental health issues. Jane also relies on her family for support, as in the extract below:

Well I know for one thing that my family's attitudes haven't changed and those are the people that matter the most, so they haven't changed, they have been very understanding and very supportive [Jane 6.169-171].

Mariam also reported that she is using a pragmatic approach to tackle the gossip about her mental illness:

I don't have to think about these people because this is not something I bought in the shop, this is a sickness, no one want to be sick so if it happens I don't care what people say what I will do is to pray to God to help me if anyone say anything let them say anything, because I don't care about what they say. I know I didn't go to shop and buy this for myself, it has happen and it's Satan who caused all these problems [Mariam 9.272-276].

The way Mariam vigorously talks about the stigma of her mental illness not only suggests a feeling of resentment, but it also shows that her resilience is suffused with cultural meanings. For instance, she makes a robust declaration and uses a metaphor to emphasise that she did not choose to suffer mental illness when she says 'this is not something I bought in the shop'; this evokes a sense that it is not her choice or fault to have a mental illness. This is also a culturally powerful way for Mariam to say that she is being unfairly stigmatised and she wants to be left alone. Those of us who have been in any open-air market in an African country can instantly recall sprawling and chaotic atmospheres that are also peaceful in the way they allow people to freely buy their merchandise. Mariam is reminding those stigmatising her that her mental illness is not like buying something in a shop: she has no choice and she cannot take it back. Furthermore, 'if anyone say anything let them say anything, because I don't care about what they say' is indicative that Mariam is sending a very strong message to those taunting her that she is resilient and oblivious to what is being said. Finally, Mariam suggests

that her mental illness is caused by ‘Satan’ and that she will ‘pray to God’ to help her. This suggests a culturally suffused complex association between evil spirits, spirituality and fatalism in her mental illness.

### **6.5.5 Summary**

This section has captured the participants’ struggles and negative experiences with mental illness in England. Participants felt that they had not been able to achieve their potential. They discussed emotionally and culturally motivated overtones linked to their opportunities in life. The conviction that negative stereotypes about mental illness are rampant in the participants’ own communities was also overwhelmingly expressed by many of the participants.

## **6.6 ‘Freaked out’**

This superordinate theme explores the participants’ personal experiences with the mental health services. It consists of four subordinate themes exploring the participants’ first reactions to admission to the wards and their experiences with the inpatient and community mental health services.

### **6.6.1 ‘It Just Completely Freaked Me Out’**

All the participants used the interview to reflect on their experiences with the inpatient and community mental health services. Many of the participants who had experienced inpatient admission described their shock and horror the first time they were admitted to the wards.

This was reflected by Kofi when he said:

I couldn’t even remember what happened. When I woke up I thought I was in prison or something, it just completely freaked me out because I didn’t know where I was...I didn’t know I had been admitted and all of that had happened because I had a massive episode for a couple of hours and then I fell asleep and

then I woke up and I was in the hospital. And then they explained to me what had happened and I was like ok...I pretty much thought that that was the end of it all like I had messed up [4.113-123].

Kofi's account is revealing of how frightening his first admission to an acute psychiatric ward was for him. Describing his experience as like being 'in prison' and his reaction that it 'completely freaked me out' conveys Kofi's feeling that something more catastrophic was happening to him. I would also suggest that likening his experience to prison is evocative that he has somehow been trapped or suppressed in his personal life. Kofi's account suggests that he was troubled and confused and was experiencing a complex mixture of feelings when he says that 'that was the end of it all like I had messed up'. His narrative is evocative of a sensation that his life has been caught up in chaos and it has been difficult for him to get free. However, a period of calm rationality on the ward helped Kofi to clarify his thinking, which gave him tremendous hope and insight:

From the initial shock of the hospital, I eventually learnt after I had left the hospital that it was a good thing that had happened because I could have been dead or ended up completely brain dead or even worse than I was because a lot of things were explained to me about what illness I had...like about psychosis and depression. It was an eye opener; I learnt a lot [Kofi 4-5.125-129].

On one level, Kofi is telling the story that the hospital admission has helped him to gain insight into his mental illness. The thought of dying or being 'brain dead' evokes a sense of complete and irreversible loss of his personhood or personality to mental illness. He uses the phrase 'an eye opener' to evoke a sense that his hospital admission has proven to be unexpectedly enlightening. Thus, the words that come to mind with regard to this statement are 'recovery' or 'on the way to recovery'. On a second level, Kofi is reflecting that his overall experiences with the services have been positive. He appears to highlight that the professionalism and

empathy of the clinical staff enabled him to come to terms with his diagnosis, saying ‘a lot of things were explained to me about what illness I had’. This led Kofi to explicitly state that his stay on the ward was positive:

So far my experience has been positive and that’s the only sort of scale I can go along with. I haven’t seen or known any other people who told me any different so that’s all I can say [Kofi 8.245-248].

Here, Kofi is suggesting that he enjoyed a positive experience on the ward. He was also unequivocal about the positive experiences of other service users. Similarly, many participants narrated that their experiences on the ward have been positive. This was evidenced when Asana said:

They just gave me everything, what you need, if you don’t have anything they give it to you because didn’t have anything so they gave me clothes which other people have left and they were so nice to me, they sat next to me, everyone was so nice to me...Yeah, yeah because everybody was so nice, they were so nice too, they were so good to me and the food they want to see you eating properly [Asana 3.67-73].

Here, Asana expresses immense gratitude for all the kindness and dignity offered to her on her first admission to an acute ward. Although, as already discussed in the previous section, her initial arrival was marked by confrontation with the nursing staff regarding her detention under the Mental Health Act 1983, her narrative is suggestive that she received truly holistic care, and her appreciation for all the staff who helped make her feel comfortable is wholeheartedly conveyed in her account. Similarly, the quality of care on the ward attracted many accounts of appreciation from other participants. For example, Mariam and Aisha reflected their experiences in a positive context:

Well the service in the ward, I have nothing to say about, I can’t say anything bad



about it, because they have not done anything wrong to me [Mariam 15.448-449].

Well to be on the ward, was better because I was having the medication, morning afternoon and evening [Aisha 5.129-130].

As evidenced by these extracts, appreciation of the services on the ward was expressed in countless ways. These accounts are evocative of the participants' sense of gratitude for the respect, understanding and empathy shown to them at a very difficult time in their lives.

On the other hand, many other participants reported that they found their time on the ward difficult and disquieting. For example, describing her early days on the ward, Tina said:

When you are in here it is very difficult to maintain your stability. It's almost as if you are thrown into the deep end. The first days were a bit shaky but now I think I have kind of got used to the environment but it can be quite humiliating to be here...The first days I just realised...you know what this is quite distressing but at the same time people have got a job to do. So if they have got a job to do, they are all going to do to their best of their ability so it's nothing personal that they will be doing, but it is really upsetting [Tina 7.194-201].

Tina's description of admission to the ward is revealing, particularly when she uses a metaphor to explain her experiences. There is a suggestion from her narrative that the impact of moving from a familiar home environment to an unfamiliar ward environment was difficult and emotional for her. Tina describes her early days on the ward as 'a bit shaky', suggesting how vulnerable she felt on arriving on the ward. It also suggests that she found the whole experience alienating, possibly due to the shock of finding herself in a new environment and dealing with new faces. She uses the metaphor 'thrown into the deep end' to tell us that her stay on the ward was emotionally or mentally challenging and nothing prepared her for that. The metaphor is also evocative of the reality shock for Tina as she soon found out that she had lost her autonomy and had to succumb to the ward regimen. It is therefore not surprising

that she describes her experiences as ‘humiliating’, ‘distressing’ and ‘really upsetting’.

Tina not only interacted with the clinical staff, but also her fellow service users. The following extract is her reflection on how she coped with other service users on the ward:

You always have different opinions and sometimes in view of the fact that someone else also is going through something. I tried not to take it personally because yes you would have the name calling and bitching I just tried to walk away from it [Tina 7.203-205].

Here, it appears that Tina has finally come to terms and overcome her initial shock and distress about admission to the ward. She appears settled and now understands the culture of the environment. She is rational and understanding and keeps clear of confrontation. She does not take the abusive language and insults directed at her by other service users ‘personally’, but tries to address them in the context of the other person’s distress. Her demeanour suggests that she has worked out how to stay out of trouble to maintain her safety. Quirk, Lelliott and Seale (2004) find that service users employ various strategies to manage risk in the volatile ward environment where risks are concentrated.

Similarly, Eva reported that she enjoyed staying on the ward as it offered a sense of security; she specifically cited the food, therapeutic interaction with staff and activities on the ward as helpful and offering some hope of getting better, but she expressed unhappiness and a sense of insecurity because of continuous discussion of her immigration status during weekly ward rounds:

We discuss my stay in the country, whether it is legal or illegal and whether I am going to stay afterwards [Eva 5.138-139].

It is essential to note that at the time of Eva’s admission, concerns had been raised about

her immigration status and therefore her eligibility to receive mental health care in England was at stake. Three levels of competing interpretations can be inferred from Eva's narrative. On one level, I would suggest that her stay on the ward is felt as a twofold stress. Eva not only has to deal with the stress of admission to a psychiatric ward, but she is facing the added stress of proving her eligibility to remain in the country or to even receive care. We can imagine the Eva's constant fear of being discharged from the ward or even deported from England. On a second level, it could be suggested that the impartiality and benevolence of the clinical staff were severely compromised, if it is true that they regularly raised Eva's legal immigration status with her. Undoubtedly, this would be an unsettling and nerve-wracking experience for Eva, as she was at the mercy of the same staff for her care, who had unqualified power to report her to the UK Border Agency (UKBA) for potential deportation. On a third level, Eva's experience reveals the pervasive power imbalance on the ward. Thus, the feelings of powerlessness she endured are illuminating in her narrative.

#### **6.6.2 'An Adopted Child or a Step-child'**

The descriptions of the participants' experiences with the services seemed to provide a platform for them to reflect deeply on how their socio-cultural contexts are affecting their experiences with the services. Tina reflected on her experiences using a metaphor:

Sometimes...you end up feeling like well if you're in an adopted country maybe you are being treated like an adopted child or a step-child. I don't know how they are treated but normally the step-parents are never given credit nor does the step-child. They feel like they are not part of the family. Sometimes...that's how somebody coming from Zimbabwe and living here ends up feeling; maybe I'm getting the step-child kind of treatment. It's like really, 'you know we will deal with someone who is British first or whoever and then you come last' [Tina 11.337-343].

In this Tina invokes the relationship between an adopted/step-child and an adopted/step-parent to convey her perception of the mental health services in England. Several points of interest can be noted from her complex narrative above. First, Tina is invoking the supposed acrimonious relations in a step-family or blended family to convey her experience with the mental health services. Though this is open to dispute, in many cultures a step-child is presumed to be less favoured than a biological child. So, if a parent was being abusive, the step-child might get worse abuse than the biological child. Thus, it is expressive that Tina is using the metaphor of a step-child/step-parent relationship as a culturally powerful analogy to convey a sense of neglect, bitterness, insensitivity, or even hostility from the English mental health system. Second, Tina states that 'normally the step-parents are never given credit nor does the step-child'. By analogy, if 'step-parents' are taken to be the mental health services, and 'step-child' to be Tina, then this is suggestive that Tina somehow accepts that she is not giving enough 'credit' to the mental health services for the support and empathy it has offered her. Tina states that 'I'm getting the step-child kind of treatment' which could be taken as a euphemism for unfair preferential treatment at her expense, or prejudice, bias, inequity or discriminatory treatment from the services. The contradiction Tina expresses here highlights how the mood of a disaffected service user can become volatile when they perceive that they are not being treated fairly. Finally, Tina seems to make a direct reference to the fact that there is a lack of fit between her experience and her cultural background when she says that she is not considered as 'part of the family'. This is suggestive of Tina's feeling that she is alienated from the mental health services.

Interestingly, Tina shifted the focus of the conversation from herself and attempted to

describe her perception of how other service users feel about the English mental health services:

I think people appreciate the services offered but there are some cultural differences in the sense that sometimes people are expected to be treated the way they are treated within their culture because if you are treated any different it becomes a problem [Tina 11.349-342].

Here, Tina appears to be acting as the mouthpiece for other African service users, if not all minority service users. Although she thinks that many of the service users are grateful for the services they are receiving, she cautions that services must be delivered in the context of cultural sensitivity. It appears that her wish is twofold: she wants the services to be understanding of other cultures and she does not want to be treated with contempt because of her cultural background, and she indicates that failure to do so will foster discontent. In speaking of this, the narrative thread quickly escalated to Tina's frustration that she is not being treated with sensitivity on the ward:

My concerns are not followed up and almost as if they are brushed off or put to the side...A typical example being that I've had things missing in the ward that hasn't been followed up on when I asked for. Ok fine, these are valuables can I have at least one search and I ended up being brushed off. It's only now that I've gotten feedback but the whole of November and we are now in December and nothing has been done up until now and this happened at the beginning of November and it's now December and I haven't got any feedback [Tina 11-12.356-368].

Tina's narrative is very different from her wishes discussed above. As evidenced by the analogy of 'brushed off or put to the side', Tina is hinting that she is angry and disappointed that things important to her are ignored by staff, and that she feels let down by staff who are dismissive and don't take her complaints seriously. I would argue that her narrative conveys an undertone of construction of negative experiences characterised by disempowerment,

loss of identity and loss of a sense of control over her life.

Despite her disappointment, Tina did not think that she would necessarily get empathy and understanding if assigned to African staff members:

You know what; I don't really ask somebody in regard to where they come from so nine times out of ten you will find that I don't even ask. So I just treat staff like staff and I don't segregate if they are from Zimbabwe and they are going to treat me better, I just consider if you're staff you're working on the same team and that's it [Tina 12.379-382].

In this Tina is suggesting that the racial/ethnic identity of professionals is not necessarily linked to a better experience with the services. Moreover, her narrative is suggestive that service user-professional racial/ethnic matching may not be an important predictor of cultural sensitivity of service provision.

### **6.6.3 Support from Professionals**

Many participants constructed positive experiences with the services, either as inpatient or community service users. For example, following discharge from the wards, many continued to receive support from the community mental health services, and these services were reported as being helpful. The following participants reflected on the practical support they were receiving from the community mental health services:

They came home and assessed me and the team made sure that I won't go back to where I was before...My care coordinator visits me and reminds me about appointments and then would take me there. So they do a lot [Ama 8.222-225].

I have somebody who comes to my house every day. She helps me with laundry and things like that...She helps with medication [Jane 7.198-202].

They come once a week to check everything; they talk to me to see if everything is ok and to see if I am taking the medicine [Asana 7.210-211].

The impression from their narratives is that the services are compassionate, sensitive and proactive in supporting them in their recovery. Some participants narrated how their community clinicians have been inspirational in promoting their social inclusion and integration into their families and communities:

My CPN (community mental health nurse) has been very supportive because I've had two CPNs. The first one was very supportive that has helped me cope with mental health, and the second one...used to come and see me once in a while. She would encourage me to get out, to see some friends, to do some activities though I would say no, at least to know that someone cares for you and is supporting you through all this are comforting and it's good to know as well [Zena 10.303-309].

Support that I have at the moment is what has kept me going. I've had support from Community Freedom (name changed), a social worker, CPN, general outpatient appointments and plus my medication so it's giving me some form of routine and I do volunteering for some charity...And that's something positive that I look at the moment...a support worker from Community Freedom comes in on Monday and Friday mornings to come and see how I am doing; see if I am doing my day to day tasks, my mood and just be general well-being...At the moment (care coordinator) is helping me with interviews, when I go to doctors' appointments, helps with my finances...how I manage my money and paying off debts and also organising my psychotherapy that I go to once every two weeks [Kofi 6.178-190].

Others spoke about the therapeutic support they had received from clinicians:

I used to go and see my psychologist...and my social workers. I talk to them about how I feel and stuff and they usually have a solution to how I feel and stuff [Bobby 5.198-200].

She asks me how I'm feeling, how the voices are...when the voices are strong, I do need the regular support because she does talk to me, advise me to calm down...I don't feel stressed [Aisha 6.148-153].

Finally, professional support was not limited to the community; other participants also recalled the support they received on the wards. For example, Tina explained how she

benefited from occupational therapy (OT) sessions on the ward:

Well here we also have OT and session that have coping strategies, we've got recovery sessions. There are a lot of sessions that they offer here that help in a way because when you are talking to others or in a group it kind of comes together [Tina 11.331-333].

#### **6.6.4 Support from Family and Friends**

There was a general sense of gratitude in the participants' narratives, especially when they spoke about people they believed had helped transform their lives to make recovery a possibility. Participants reported that they felt safe and comfortable being around close family members and friends and they appeared to frame their experiences in the context of strong family and community networks. This was demonstrated by Tina when she said:

I think family has helped me to cope better. And being able to say to them when I need my space and they will just back off...and are there when I need them closer or to start discussions, it's been better for me that way...because there is a stigma that is attached but still I think family being family and them knowing you more than most people, they are able to identify that these things should have never happened to her and they question what is going on and why? So that's kind of given me that comfort of knowing that other people care [Tina 10.311-320].

Tina is appreciative that her family is acting as her bedrock as well as a source of sympathy and emotional support. She portrays her family as not only accommodating, understanding and respectful of her privacy, but also as a protective shield to withstand any negative stereotypes associated with her mental health problems. Moreover, a powerful conclusion to be drawn from Tina's narrative is that her communal world is important to her recovery. Similarly, Bobby reports that his mother is his confidant and immediate source of support whenever he is feeling unwell:

Recently I have managed to tackle the voices by telling my mum how I feel at that



present moment if I am hearing voices. She sort of understands, I tell her what voices I hear and stuff and she understands and acknowledges that and says do you want to speak to someone, you want to speak to your support worker? She is quite alert and I do appreciate that [Bobby 5.191-195].

Bobby is grateful for his mother's support and understanding of his needs. However, it is also implicit in his narrative that his mother extensively relies on professional advice to keep him going. This is a powerful indication that collaboration with family members is an important recovery impetus. Similarly, Ama reported the emotional support she gets from her family:

If I feel sick my family feels for me. They feel very sad especially my husband...when they found out they were all so sad and worried...it is difficult to put it into words but they all felt worried because of what was happening to me [Ama 7-8.190-203].

Ama's narrative suggests that she feels overwhelmed and guilty that she has become a burden to the rest of her family. Nonetheless, the interesting message she conveys in her narrative is the sense of a strong communal support and the fact that her family does not leave her to suffer alone whenever she is unwell. Similarly, Zena reflected on the support she gets from her parents:

My parents are more alert to me than most people because they are more sensitive to me. They are trying to be more caring than they used to be because then they used to be very stern with me and when I complained about that they apologised and said 'let's turn around and be more supportive' [Zena 8.247-250].

Zena's story is a touching demonstration of parental support for a young woman whose life has seemingly been hijacked by mental illness. However, a closer look at her narrative reveals that she previously suffered negative treatment at the hands of her parents. This is expressive of the fact that her parents initially stigmatised and treated her pejoratively. Zena's experience is an illustration that families can serve as a source of inspiration, or be a challenge

to recovery from mental illness. Likewise, support from close friends and community members was reported by some participants to play a vital role in their recovery journey. For example, Aisha and Ama reflected on how supportive and accepting groups of friends have been helpful and inspiring for them:

I only have two friends and they come around to see me...I do discuss my problems with them. I talk to them when I am stressed [Aisha 11.314-316].

They pray for me. Those who didn't come to the hospital they told me they prayed. When I was in hospital I wasn't allowed to use the phone, so people asked about me from my husband [Ama 8-9.232-234].

Aisha and Ama's narratives illustrate that emotional and/or spiritual support from members of their community has been beneficial to their recovery journey.

Although some participants noted the support they receive from family and friends, a few recounted how negative attitudes from family and community members were having a negative effect on their psychological wellbeing and recovery. For example, Sheku reflected on his resentment at his father's disrespectful manner towards him and other family members with mental illness:

My dad the way he puts it makes it seem like someone with mental illness is bad. The way he puts it that person has mental illness, my mother's side of the family has mental illness so when he says like that person has mental illness in our family then he tells my mum that person has mental illness the way he puts it makes that person seem like less of a person you see...I don't think he has ever asked me about my medication, he has not asked about my medication. It is just the way he is...I don't think he actually understands what mental illness is about. He has not actually understood what it is about. All he knows is that person is not well and that is all he knows. He doesn't know that it affects you in several different ways and so on. He is not the type of person to understand. He hasn't got a really good understanding [Sheku 8.258-273].

This is a complex statement in need of disentangling. Sheku was clearly upset about his

father's indifferent and seemingly unpleasant attitude towards himself and family members with mental illnesses; however, he appeared very calm and used a relatively polite tone when he spoke about him. Presumably this is because it is objectionable to show disrespect to one's parents in many African cultures. However, I would suggest that by emphasising his father's negative attitude towards him and others, Sheku is unequivocally displaying his anger and frustration at his father's attitude.

#### **6.6.5 Summary**

This section has presented an in-depth analysis of the participants' experiences with the inpatient and community mental health services. Findings revealed that participants expressed a wide spectrum of experiences ranging from shock and horror, alienation and fear of recrimination to feelings of positive experiences with the services. The following section presents detailed analysis of the participants' experiences and perceptions of meaning in their personal recovery.

#### **6.7 Focus on Recovery**

This superordinate theme offers interpretations grounded in the participants' experiences and perceptions of the meaning of personal recovery. Four subordinate themes come under this superordinate theme. The first theme examines the participants' coping strategies in recovery. This is followed by the second theme, which examines the participants' accounts of the relationship between their spirituality and recovery. The next theme examines the participants' insights into links between medication and their recovery and the final subordinate theme examines the participants' unique meanings that they ascribe to their personal recovery.

### 6.7.1 Resourcefulness and Self-awareness

Nearly all the participants used the interview to talk about the coping strategies that were helping in their recovery journeys. Many spoke about their resourcefulness in the context of participation in social activities within their communities, whilst others recounted their self-awareness in the context of exploring issues about their diagnosis. For example, describing his resourcefulness, Kofi spoke about his extracurricular activities:

I volunteer in football and sport that we have at the moment for social opportunities. We organise football session on Tuesdays and Thursdays which I attend almost every week. I don't talk about mental health with them and I think that's a positive thing because it's a separate thing away from my health [Kofi 7.195-198].

Here, Kofi is demonstrating that despite his ongoing mental illness, he is resourceful and can give something back to his community. This also gives him the opportunity to socialise and integrate into his community. It is peculiar that he states: 'I don't talk about mental health with them and I think that's a positive thing'. He deliberately avoids talking about his mental health problems when attending such activities. This suggests that perhaps he uses the community activities as a strategy or even an opportunity to reinvent himself and to overcome the social liabilities of his mental illness. Similarly, Bobby explained how he kept himself busy by engaging in leisure activities:

I keep myself busy, I do my hobbies and stuff like my artwork. I mostly do my music, I listen to music, it mostly takes my mind off things or watch television it takes my mind off stuff [Bobby 5.212-214].

Bobby's narrative highlights that being proactive and engaging in extracurricular activities can enhance a person's recovery. Likewise, Tina described her resourcefulness in the context of

helping others suffering with mental illnesses:

In the coming months or coming years I see myself as a woman that is successful and a woman that is determined and supportive in a way. Because I feel like it's something that touches my heart that it happens to people then they need the best care that they can get and they need the best support as well, so probably be an advocate that's in regards with wanting to know more about mental health [Tina 10.322-326].

Different readings could be ascribed to Tina's narrative. First, it can be assumed from the first sentence that she is indicating her resolve to recover and to regain her self-esteem. Second, she shows her intention to help others who she perceives as being marginalised because of mental illness. Third, Tina appears to highlight harrowing feelings of dissatisfaction with the mental health services, therefore it is not surprising that she has a sense of duty to extend acts of real kindness and sensitivity to those she perceives as disaffected by the mental health services. Finally, her narrative is suggestive that she is a sympathetic and empathetic person; these are also reminiscent of the qualities of humanness, one of the main conceptions of personhood in African thinking (Tutu, 2008; Tutu, 1999; Menkiti, 1984).

For Sheku, his self-awareness was expressed in the context of his mother's mental illness:

I've got a good understanding of mental illness because when I found out my mother was mentally unwell she was in a hospital in Austria and so on, I kind of had mental health experiences with my mum really so I kind of at a younger age I kind of watched out for symptoms for myself...but I did never quite know what symptoms to watch out for I watched out if started getting unwell to that level I started watching out for myself things or doing certain things. I wasn't quite successful at that really as I myself wasn't too well, I wasn't too well [Sheku 6.200-207].

Several interpretations could be drawn from Sheku's narrative. First, he gives the impression that his mother's mental illness provided him with the opportunity to become more aware of

the ailment. There was a certain irony in this account, but Sheku appeared to be too emotionally inept to acknowledge this. He did not show any emotions when talking about his mother's mental illness. This is odd given that we would expect people to be emotional when talking about traumatic childhood events. Arguably, such childhood experiences have desensitised him, and perhaps he has come to regard mental illness as something familiar. Second, finding out that his mother is suffering from mental illness at a very young age did not depress his spirits; rather it motivated him to monitor himself to detect any signs that he is developing similar symptoms. Many children would be ashamed or embarrassed that one of their parents was suffering from such an illness. Undoubtedly, Sheku's experiences are poignant, but equally they are courageous. Third, his narrative is evocative of a conviction of transference of his mother's mental illness to him, hence his vigilance in watching 'out for symptoms' in himself. Sadly, he concedes that his attentiveness was in vain and he was unsuccessful at avoiding mental illness. When Sheku says that 'I myself wasn't too well, I wasn't too well' he is showing retrospective insight, but perhaps he is also implying that he experienced mental illness many years before he was officially given a diagnosis. Sheku's experiences are a powerful indicator that self-awareness does not automatically mean avoidance of mental illness. However, his story shows that becoming self-aware can lead to a pathway to recovery.

### **6.7.2 'There is Anointing Everywhere'**

Without any prompting, spirituality and belief systems were acknowledged by almost all the participants as very important in their recovery. Although the participants did not mention any specific religious affiliation, it was apparent in their narratives that most were conveying

deep faith in the Christian philosophy and faith-based healing. Many professed that God and their spirituality provided hope for recovery and comfort. For example, Ama spoke about how she sought answers and assurances from God:

I am a human being, if anything happens I will ask God. I rely on him and he is the one who looks after me...in him we should trust...So I believe in God that with him nothing would happen to me [Ama 4.135-144].

Ama is persuasive in her narrative that becoming closely connected to God is providing her with a deep sense of peace and comfort, and possibly a source of treatment. Her account also suggests that she is somehow passive and is not taking active responsibility for her own recovery, as she appears to accept that a spiritual miracle will inspire her recovery. This was also echoed by Mariam when she said:

I know there is God who created me, who created the heaven and the earth, why should I worry; he is the only one who can help me, why should I worry. My worry will not solve the problem is only when the time comes God will solve the problem [Mariam 12.374-376].

Mariam's narrative declares that spiritual deliverance is her first line of treatment: it is only God who can offer her the prospect of recovery, rather than the mainstream mental health services. Arguably, her relative passivity towards the mainstream mental health services is due to her staunch faith in spiritual deliverance. This was evidenced when she said:

I just pray to God that he will give me good health and to go forward and live on my own, yeah... I believe he will help me to become well, start to go to work and pay my bills and my rent [Mariam 4.114-119].

Mariam's narrative evokes her reliance on the divine kindness of God for her resourcefulness and self-sufficiency. Zena also reported that spirituality was having positive effects on her recovery:

When I was diagnosed with schizophrenia, mum would take me to different churches. Before I was diagnosed she would be confined to the Catholic church but now she's open to any churches like the Pentecostal churches...she would go to the Pentecostal churches and also go to the Catholic church, though she prefers the Pentecostal churches because she said that there is more anointing there though I don't think that's the case. There is anointing everywhere but she prays more and I've learned to pray more as well and have faith in God that he's going to be with me no matter the case that I'm in...I think it's helping me because I'm able to rely on God. I'm able to rely on someone who can take care of me and make sure I don't get sick again, guiding me to the right path and being SDA helped me...other denominations as well [Zena 7.188-206].

Here, Zena recounts how she and her mother identified spirituality and religion as one of the main sources of treatment that they really trusted, shortly after she was diagnosed with mental health problems. Though her pursuance of multi-denominational spiritual deliverance stands out from the rest of the participants, they all had a common characteristic of seeking God's intervention in their recovery.

### **6.7.3 Medication**

All the participants expressed their desire to get better and seemed to construct their recovery within the context of taking medication. However, the narratives revealed varied and complex views about medication. This was expressed as a continuum, where at one end some participants reported positive experiences with medication, whilst at the other end some reported bad side-effects from medication. Some of the many narratives that spoke positively about their medication included the following:

I like my medication because it makes me feel better [Eva 12.316].

My medication, yes it really helps especially the antidepressant medication. Depression is one thing I know I haven't beaten yes so it really helps because I would be really depressed and would end up indulging in things...so it really helps. It takes my mind off things as well and the hearing voices the medication has helped with that as well [Bobby 6.245-249].



It made me feel better since I started taking it...it's making me feel good...I don't have any funny feelings...the voices...they are not strong as before [Aisha 3.64-68].

The narratives above suggest that medication is playing a key role in the participants' recovery from mental illness. There is an impression from their narratives that medication is not only reducing symptoms, but it has inherently inspired optimism and also triggered insight into the participants' mental illness. Despite this, some of the narratives revealed varied and complex views about medication. For example, Kofi described his initial reluctance in taking antidepressants and anti-psychotic medications because of his own and his brother's preconceived fears:

Initially I found it very difficult taking medication because I think everyone has certain ideas about antidepressants and anti-psychotic medication. I just assumed that it will make me crazier or get hooked...Initially I was completely against it because my brother was quite negative and told me not to take them. I just felt it wasn't worth taking because it wasn't really going to make much of a difference...I think there was a general lack of knowledge in that particular subject in his part [Kofi 7.213-226].

It is clear from this extract that Kofi's negative preconceptions about medication were self-instigated and then strengthened by his brother. For Kofi to state that 'I think there was a general lack of knowledge in that subject in his part' is evocative that close family relatives can be intrusive and influential in reinforcing negative or unsubstantiated beliefs about issues relating to mental illness. Equally, the statement is indicative that Kofi is showing retrospective insight into his misunderstanding or misinformation about antidepressant and anti-psychotic medications.

Some participants reported that taking medication was not their own choice, but that of

people in charge of their care. For example, Eva, who was receiving care on the ward, reported that taking medication was the 'choice of other people' [Eva 8.231]. She uses 'other people' to refer to the psychiatrists and nurses in charge of her care. Her account is also strongly suggestive that she was coerced into taking medication. However, such practice is common for a sectioned patient on a psychiatric ward. Similarly, Jane reported that getting a depot injection on the ward is something she has 'to go along' with:

Sometimes when you're here and you don't want the injection you feel as if you just have got to go along [Jane 7.217-218].

Nonetheless, here Jane's account suggests that she feels coerced into taking her medication. The impression from her account is that she feels trapped or even like she is being held hostage on the ward, and that she has to act as an obedient hostage by complying with her depot injection, something she fundamentally disdains, in order to secure her freedom. Jane's experiences in relation to medication are one of courage, resistance and acceptance.

However, one participant pragmatically explained that she could only be coerced to take medication when she was on the ward:

The doctor can only force me when I am in the hospital, but when I go home no one will force me to take the medication [Mariam 13.405-406].

In this Mariam makes a direct reference to 'the doctor' and 'hospital' as symbols of coercion and dictatorial elements in the mental health system. Her narrative is also suggestive that true autonomy is only guaranteed in one's home environment and not in hospital. Despite this, Mariam reasonably explained that taking medication would prevent re-hospitalisation:

Well, for now I need the treatment because when I stop taking the treatment then

I will end up in the hospital, so the most important thing is to consider the treatment because it can help me to stay out of hospital...it has a different smell like medicine, I don't like hospital but there is no choice for me...I don't feel happy to be in the hospital. I like to stay at home, go to work...but what can I do? [Mariam 6.162-175].

Mariam is using 'treatment' to refer to medication in the above. She is expressive of her dislike for both medication and being in hospital. Even the odour in the hospital environment compounds this dislike. Therefore, it appears that her decision to accept her medication is considered the lesser of two evils; Mariam would rather take the medication than stay in the pungent hospital environment. Mariam declares that she would prefer to be at home and to 'go to work', suggesting that she is ambitious, resourceful and active in her recovery journey, but it is interesting how she seems resigned to the fact that she has no control over her own fate when she rhetorically asks 'what can I do?' I would suggest that Mariam's experiences are defined by powerlessness and the fragmentation of life ambitions.

Ama also gave pragmatic reasons for why she takes her medication:

It feels a bit awkward to me. But they want me to get better so I will stick to my medication...even myself if I am not keen on taking any medication, but I feel that it is not by force to take it...but they try to make me get my life back [Ama 13.357-361].

Ama's narrative is critical and pragmatic. Even though she views her medication as an inconvenient necessity, she reasons that it gives her back control of her life. Furthermore, unlike many participants, she concedes that she is not coerced to take her medication when she says 'I feel that it is not by force to take it'. However, Ama's circumstances need to be taken into consideration, given that she is a community service user and community service users are typically not supervised in taking their medication.

The perception that anti-psychotic medications are ineffective provided the opportunity for one participant to travel to her native country to try the 'native herbs and medications':

Well I did come to the point when I said maybe this thing is not working let me try some native herbs and native medications...native way; that's why I went to Sierra Leone...to try it in another way...they boil it. I go under a duvet and cover my head and hit my body with it seven times a week...you rub it all over your body when going to bed. You wash with it and then you drink some...because I want the voices to go away...it's not working...I've tried three times it's not working. With different people, different people do the medication, everybody share their experience...It's the same, similar thing; I don't see any difference [Aisha 4.97-116].

Aisha was visibly sad and disappointed when she said that the 'voices' were 'still not going'. Several readings could be taken from Aisha's narrative. First, her account is expressive of her frustration about the efficacy of the conventional anti-psychotic medication and this might have triggered a loss of confidence and thus her desire to seek alternative treatment. Second, her vivid description of the administration of the traditional medicine in Sierra Leone suggests that, like the mainstream mental health services in England, the supervision and administration of traditional African medicine is also a disempowering experience. Third, there is an undercurrent of perplexity and a lack of confidence in both approaches to treatment when Aisha says 'it's the same, similar thing; I don't see any difference'. I would therefore suggest that Aisha's lived experience is one of disempowerment and disappointment.

Some participants also spoke about the disabling side-effects of medication, such as weight gain, tiredness, loss of interest, memory loss, perceived loss of intelligence and speech difficulties. For Tina, the side-effects and prospect of being forced to take medication for the rest of her life compelled her to threaten to leave England for her native country for good:

Well when I looked at the side-effects I was a bit sceptical about what was going to happen because in view of the fact I don't have any children. And that's a major concern that I wouldn't want my body tampered with and affect the future of my kids...I would absolutely say I don't think I want that because if I'm supposed to take the depot injection for a long time why do I have to be in this country, I don't have to be here...I would go back to my country which is Zimbabwe...Because I feel like if it's for a long time, why do I have to suffer in this country? I don't have to go through all of this...if it is a prolong thing there is no need for me to be in this country...Right now I think it's stopping me from doing lots of things...I can't be stopped by a two-week injection...I'll go back to Zimbabwe and not have to go through all of this [Tina 7.207-237].

Tina's narrative is complex and requires unravelling. It appears that not only is she preoccupied with the terrible side-effects of the medication, but she is also afraid that the medication might have an effect on her fertility and that she might not be able to have children. This predictably persuades her to doubt or have reservations about the psychotropic medication being prescribed to her. I would also suggest that the negative social and cultural consequences of becoming childless perhaps contribute to her scepticism about psychotropic medication. By stating that 'I wouldn't want my body tampered with and affect the future of my kids', Tina is perhaps using a biblical analogy to convey the idea that her body is a shrine or sacred place being preserved for conceiving and nurturing her offspring and thus she does not want her body to be contaminated by psychotropic medication. Finally, Tina demonstrates that she is assertive and eager to reclaim control of her life by fiercely protesting about the fortnightly injection and even threatening to 'go back to Zimbabwe'. The tenacity in Tina's voice here was unprecedented considering the universal belief that many service users have no voice in their own care. Other participants also spoke about their experiences with the side-effects of medication; Eva and Jane described bodily changes they had experienced because of their medication:

I do not like taking medicines...I put on a little weight [Eva 7.214-216].

I never used to talk like that. I used to talk very clearly. My face is puffier. My face never used to be like this [Jane 6.179-180].

Eva and Jane's narratives suggest that they were once proud of their attractiveness, but now they are not. There is an impression in their accounts that Eva and Jane have become sensitive to their body changes as a result of their medication, and this is arguably affecting their self-confidence. Zena also described the side-effects of medication in the context of perceived behavioural and intellectual changes:

The medication was making me feel tired, I was finding it hard to read books, I lost interest in a lot of things...I am taking medication that is making me feel tired, making me lose a bit of my memory, lowering my IQ and making me have not good concentration on anything but I'm trying my best to cope with that [Zena 8.227-229].

For Zena, her experience of taking medication is defined by lethargy, lack of pleasure, memory loss and perceived loss of intelligence. For someone studying at university, the perception that psychotropic medication is 'lowering' her 'IQ' and affecting her 'concentration' could be demoralising and distressing. However, Zena demonstrates her resilience and determination to carry on when she says 'I'm trying my best to cope with that'.

Despite the numerous reported side-effects, one participant was pragmatic about this:

There is nothing I can do about the side-effects. I think all medications have got side-effects. There is nothing I can do [Asana 4.108-109].

There is an indication of resignation and pragmatism in the comment above. Asana has given up and suggests that there is nothing she can do to stop experiencing the side-effects that come with her medication. She backs her reasoning with the philosophical position that 'all

medications have got side-effects', thereby suggesting that it is important to weigh the pros and cons of all medications.

#### **6.7.4 The Meaning of Recovery**

All the participants used the interview to reflect on the unique meaning they gave to their personal recovery. This was framed in multidimensional ways including being pragmatic, resilient, hopeful and optimistic of living a normal and ordinary life. For example, many framed the meaning of recovery in the context of being pragmatic and accepting their fate in good faith. This was evidenced when Mariam said:

This is life, life is full of risk, life is full of trouble, especially sickness, this is our enemy, our greatest enemy is sickness death, these two things are our enemies...yeah, I cannot change anything about it, so I just have to accept it [Mariam 14.409-412].

Here, Mariam is not only showing pragmatism in accepting her mental illness, she is also showing strong emotional abilities to cope with her problems. The only word that comes to mind with regard to this is 'resilience'. Some participants also framed the meaning of their recovery in the context of hopefulness and optimism about the future:

Because I just look on the bright side, there is nothing that is hidden that will always remain hidden, things will always come out in the light...Because I have everything to look forward to, I have a bright future to look forward to and that's basically what I focus on...It's just looking ahead and seeing that you will find the love, and dignity will be restored once again and just being optimistic [Tina 6.185-196].

Tina's narrative is surprisingly positive for a person who has seemingly lost her personhood to serious mental illness. The source of her positivity appears to be inspired by her religious or spiritual beliefs, which is evocative when she says that 'there is nothing that is hidden that

will always remain hidden, things will always come out in the light'. I would submit that this statement is inspired by a biblical parable in Luke 8:17 and Mark 4:22 that counsels Christians not to live in secret or they will forever grope in darkness. Jane is perhaps making an analogy that having a mental illness is like living in the darkness, but she is hopeful and optimistic of her recovery and reclaiming her personhood and respect. Bobby also framed the meaning of recovery in the context of hopefulness and optimism when he said:

I am hoping to finish college and go to university and after university get a proper job in the music industry and open my own studio [Bobby 6.239-240].

Bobby is outlining his understanding of recovery in the context of attaining higher qualification and gaining successful employment. His narrative is also suggestive that he wants to improve himself, become productive and play an active role in a larger society.

Tina further framed her perception of recovery in the context of living a fulfilled life:

I mean it's just living a much more fulfilled life, able to work and start my business and able to have children, a family and a husband. The normal things that every woman wants, that's what I want [Tina 10.305-307].

For Tina, recovery is about having a happy family, being productive and living life to the fullest. Her account is expressive that, for her, recovery is about finding contentment in life. However, I would suggest that by focusing too much on her future accomplishments, Tina may be inadvertently devaluing her present worth. Importantly, I would suggest that Tina draws on her culturally available stock of meaning to frame her perspective of recovery, because most traditional African societies are pro-family (Gyekye, 1996) and pro-natal (Nukunya, 2003).

Other participants reflected in their narratives that recovery is all about living a normal and



ordinary life. For example, Zena expressed this in the context of enjoying routine and leisure activities:

I think what I'm doing now is proving that I'm fully recovered because I'm talking to parents, I'm listening to music, I'm watching TV, my mind set has come back because this is what I enjoy to do when I'm in Zambia. I also cook for my mum when she's not around, though she cleans the house most of the time but I'm able to do what I used to do [Zena 7-8.222-225].

Zena appeared to frame the meaning of her recovery in two different contexts: process and outcome. First, her narrative is suggestive in that she is 'proving' herself, immersing herself in daily routine and leisure activities. Therefore, for her, recovery is an ongoing process encompassing self-concept (Silverstein and Bellack, 2008). Second, to state that 'my mind set has come back because this is what I enjoy to do when I'm in Zambia', is indicative that Zena is leaning towards the notion that recovery is a return to a premorbid state of function (Le Boutillier et al., 2015), a facet of the clinical conceptualisation of recovery. Thus, Zena's conceptualisation of recovery appears to incorporate both personal and clinical recovery.

Some participants expressed the meaning of their recovery in the context of being able to participate in social activities and relationships. This was evidenced by Sheena when she said:

Going out to watch a movie, going to church...going to work...doing things, anything that will give me ease and make me happy [Sheena 8.246-247].

Here, Sheena is clearly suggesting that social relationships or engaging in meaningful social activities is important to her recovery. Stating 'anything that will give me ease and make me happy' conveys that she is perhaps currently excluded from many social activities due to her mental illness. Similarly, Jane's perception of recovery was in the context of enjoying everyday

activities:

If I'm healthy, if I'm going out, dancing without monitoring...Healthy means doing things without monitoring. Doing your daily care, I have to go to the bathroom with no monitoring. I have to do my daily tasks with no monitoring [Jane 7-8.211-215].

There is an undercurrent of focus on lack of autonomy and power inequality in Jane's narrative. Thus, she appears to frame her understanding of recovery in the context of being healthy, engaging in social activities and regaining her autonomy. For Jane, recovery is about self-appreciating and doing basic things in life that most of us take for granted, such as going to the bathroom alone.

Some participants framed the meaning of their recovery in the context of gaining employment and finding suitable accommodation. This was evidenced when Eva said:

To find a job and better housing...to improve my status and accommodation [Eva 14.388-394].

Eva expresses the conviction that getting a job and decent housing are vital to her recovery. Her account suggests that she is experiencing rejection, stigma and low self-worth because of her mental illness and therefore feels that she needs to work and get decent accommodation in order to improve her image in society.

As already discussed, many participants reported that medication played a positive role in their recovery. However, defining recovery in the context of medication evoked two responses: finding the most effective medication and stopping taking medication. For example, Sheku framed his recovery in the context of finding the right medication:

To be honest I am waiting to see if I can find a medication that can keep me on a level...just something to keep me a bit calmer every day so I can carry on with everyday life [Sheku 11.369-372].

For Sheku, finding effective medication to control his symptoms is fundamental to his recovery. Therefore, he frames the meaning of recovery in the context of continuing to take medication. However, the opposite is true for Zena when she says:

I think when I stop taking my medication I will know that I will not need the services anymore [Zena 10.346-347].

For Zena, the meaning of her recovery is the discontinuation of her medication. In spite of the clear contrast between Sheku and Zena's accounts, it is clear that their perspectives about recovery in fact converge upon clinical recovery or the scientific definition of recovery, considering the emphasis they both place on medication.

Some participants framed their perspectives of recovery in the context of symptom reduction. This was evidenced by the narratives of Eva and Aisha:

When I stop hearing voices [Eva 123.336].

If I stop having the voices, they are not strong, they are normal, I start doing what I was doing before. Then I will know that I will no longer need the services [Aisha 13.374-376].

Eva and Aisha's narratives appear to specifically emphasise cessation of symptoms or even 'cure' and thus arguably draw on the clinical definition of recovery. However, by wanting to 'start doing what I was doing before', Aisha is moving beyond the proverbial 'cure' embedded in the clinical definition of recovery and defining her own perspective of psycho-social functioning, as suggested by Harrow et al. (2005) and Liberman et al. (2002).

Furthermore, there were instances in which some participants framed their perspectives of recovery in a multifaceted manner. This is evidenced when Bobby says:

I will know when I don't hear the voices and stuff and I am doing positive things more positive things and I resist indulging in the wrong things and I am really focused on my life and thinking I need to take this a step further, get a job and be on my own two feet. The proof will be there when I know what I have achieved [Bobby 6.234-237].

I would argue that Bobby's perspective of recovery is multifaceted and it incorporates scientific or clinical recovery, personal recovery and social processes of recovery. First, I would suggest that there is an undercurrent of scientific or clinical recovery when Bobby states 'I will know when I don't hear the voices', as he appears to put emphasis on a 'cure' or elimination of symptoms. Another facet described by the narrative is that Bobby is attempting to overcome his mental illness by making a concerted effort to change his lifestyle and to become resourceful with regard to employment. All this suggests that Bobby is putting emphasis on personal recovery and social aspects of recovery, respectively.

Some participants framed their understanding of recovery in the context of the future or time. For example, when asked how she would know she had recovered, Eva replied that:

Only time will tell [Eva 12.329].

Eva believes that she will not know she has recovered until sometime in the future. Thus, she appears to frame her recovery with the future and hope, or hope with regard to what she anticipates in the future. This was echoed by Sheku when he said:

Recovery takes time really; mental illness is all about time. The medication you are given might help in some cases but in some cases, it is all about time. They may give you a high dose of medication to help you get through your illness but it

is just time. For me all I needed was time in hospital time away from my environment...The hospital gives you that time in a quieter place and then settle down and then give you that opportunity like time to recover. Apart from the medication the environment you are enables you to recover more efficiently [Sheku 5.148-158].

Sheku is emphatic in his conviction that recovery is something that takes place in the future. However, his narrative is suggestive that recovery can be enhanced by medication and the therapeutic hospital environment. Therefore, Sheku's narrative is depicting recovery as a personal journey into the unknown future. His account also suggests that recovery is a clinical and social process as it can be facilitated with medication and the therapeutic hospital environment.

Some of the participants framed their meanings of recovery in the context of what the doctors and nurses had told them. For example, Eva and Kofi framed their understandings of recovery in the context of the nurses' opinions:

I will get better according to the nurse; she will probably ask me to leave [Eva 12.332].

I guess when my CPN decides when I am fit enough to be discharged to the outside world [Kofi 7.208].

This was echoed by Asana when she said that 'the doctor' would tell her when she had recovered:

When the doctors say I don't need the medication anymore...Yeah because it's good for me, they are the ones who have to guide me and tell me what to do for the best. They are the ones who will tell me I am ok now and I can stop taking the medication [Asana 8-9.245-254].

The narratives by Eva, Kofi and Asana are powerful indications of how these participants

lacked the autonomy and self-control to make decisions about their own care, having to routinely rely on clinicians to inform them of their recovery. I would argue that their experiences are those of disempowerment.

Whether the participants were defining recovery as personal, clinical or social, there were many instances in which they identified pertinent issues such as financial, housing and other family and social problems as impeding their recovery journey. For example, Mariam narrated how her struggle to pay her bills and rent was distracting her stay on the ward:

Well as I say, when I have been in the hospital, I am so worried about my rent and my bills, because in the country we are staying now if you pay your bills you don't have problem, if you pay your rent you have a place to sleep, if you don't pay you will be homeless [Mariam 10.294-296].

For Mariam, her lived experiences are defined by apprehension and financial difficulties. It seems inevitable therefore that these experiences will impede any progress towards recovery.

#### **6.7.5 Summary**

In this section, factors impacting the participants' recovery were contextualised. Analysis of data established four subordinate themes: resourcefulness and self-awareness; 'there is anointing everywhere'; medication; and the meaning of recovery. Analysis provided rich descriptions of the subjective perceptions and conceptualisations of recovery.

## **CHAPTER SEVEN: DISCUSSION AND CONCLUSION**

### **7.0 Introduction**

The aim of this chapter is to situate the thesis in the wider context of the existing theory and literature. Thus, in this chapter the discussion returns to the question the study began with: what are the lived experiences of Black African service users (BASUs) in England recovering from mental health problems? The aim was to explore and understand BASUs' experiences of recovery in relation to their mental illness.

Twelve participants who identified themselves as BASUs were purposively selected and narrated their experiences through semi-structured interviews; these interviews were then analysed with the idiographic perspective preferred by IPA (Smith et al., 2009). Five superordinate themes were discussed in the findings chapter. The first theme – 'it is different in Africa' – covered the participants' migration trails to England, their sense making of mental illness and sentimental feelings about Africa. The second theme – 'it all started in England' – focused on the meanings the participants assigned to their mental illness, as well as experiences leading to first contact with the mental health services. The third theme – 'shattered' – focused on the participants' sense of devastation at being diagnosed with mental illness. The fourth theme – 'freaked out' – explored the participants' personal experiences with the mental health services in England. The final superordinate theme – 'focus on recovery' – concentrated on the personal meanings that the participants assigned to their recovery.

This chapter begins with a discussion of contributions to knowledge and understanding of

recovery, which is then followed by a detailed discussion of the participants' experiences within the context of the existing literature and theoretical frameworks. The limitations of the study are then presented, followed by clinical implications and suggestions for future research. Finally, the overall summary of the research is provided.

### **7.1 Contributions of This Research in Promoting Knowledge and Understanding of Recovery**

Using IPA to explore in detail how the participants make sense of their personal and social world (Smith et al., 2009), this study provides an empirical and theoretical contribution to an understanding of experiences of recovery from the perspectives of Black African service users in England. The following are key contributions that are consistent with previous research into recovery.

First, this study makes an important and unique contribution to the recovery literature by demonstrating that the recovery process for the participants is largely socio-centric or communalist, unlike the Western concept of recovery which is more ego-centric or individualistic (Bhugra, 2005; Kusserow, 1999). For example, Mezzina et al. (2006) found that many of their White and Western participants focused on their individuality and independence rather than interdependence in their recovery journeys. This sharply contradicts the participants in the present study, who regarded communal belongingness as an important aspect of their recovery. The participants overwhelmingly attributed their recovery to a closed social network of family, friends and helpful professionals.

Second, another significant contribution to knowledge is that my familiarity with the participants provided a nuanced and unique insight into their experiences. As a Black African,



I shared unspoken understandings with the participants, with regard to certain expressions that relate to cultural contexts, as well as non-verbalised facial expressions and hand gestures that did not need interpretation (Johnson-Bailey, 1999). For example, I did not perceive the participants' behaviours as incongruent when they smiled whilst speaking about difficult or emotive subjects because, as a Black African, I have intimate knowledge and understanding that such a gesture is also a sign of despair or something beyond description. I also did not consider participants' optimism about recovery, for example, through a divine intervention, as delusional thoughts or incomprehensible, because I recognise and identify that many people from Sub-Saharan Africa are deeply religious and optimistic for better lives (Mbiti, 1990; Turaki, 2006). Thus, this research makes a contribution to knowledge, not only because of my experiential and cultural knowledge as an insider, but also the practical knowledge or understanding of human behaviour. As a Black African, I had a definite advantage in being familiar with the participants from the outset and I could, in one way or another, understand their perspectives better than an outside researcher (Chavez, 2008).

Third, the study makes a useful contribution to knowledge by confirming that BASUs' conceptualisations of recovery are just as complex and multi-dimensional (Whitley and Drake, 2010) as those of other ethnic groups. A unique contribution of this research is the participants' overwhelming dependence on their culturally available stock of meaning to make sense of recovery. Arguably, the incorporation of the participants' cultural perspectives into the study creates a holistic and integrative understanding of recovery.

The fourth contribution is the extension of knowledge by integrating the concept of resilience into recovery. This is consistent with other studies, such as Kalathil (2011), that found

resilience to be an appealing quality that allows people to overcome life catastrophes associated with mental illness.

Fifth, from the contextualisation of the participants' accounts, it emerged that their identities as Sub-Saharan Africans are vital to their recovery journeys. The participants' use of socio-cultural contexts to give meaning to mental illness was particularly noteworthy. In the literature that I reviewed, I was unable to find studies that have examined how people from Sub-Saharan Africa find that living in England's ethnic, social and national identities affects their recovery from mental illness. Given that racial, ethnic and cultural identities are an integral part of people's perceived identity (Bhugra, 2005), this research has offered an insight into a novel and innovative approach to exploring and understanding BASUs' experiences of recovery from mental illness.

Sixth, this study makes an important contribution by revealing that most participants expressed positive experiences with the English mental health care system. This contradicts what is reported in the literature, that many Black service users receive coercive and discriminatory mental health services (for example, see Care Quality Commission, 2014; Department of Health, 2005; Littlewood and Lipsedge, 1997; McKenzie and Bhui, 2007, Singh, 2007).

Seventh, this study makes an important contribution to the mental health literature by detailing the migration trajectories of the participants. The study also confirms the links between migration and mental illness, which is well reported in the literature (e.g. Bhugra, 2004; Cantor-Graae and Selten, 2005; Cantor-Graae et al., 2003; Dealberto, 2010; Selten et

al., 2005; Zolkowska, Cantor-Graae and McNeil, 2001).

Eighth, this study helps to bridge the gap between mental health research and Sub-Saharan African service users. There is urgency for researchers to use a broader range of research designs to investigate the experiences of mental health recovery for minority cultures (Leamy et al., 2011; Slade et al., 2012). Thus, this study utilises an IPA qualitative approach to explore and understand the lived experiences of the participants.

Ninth, this study has drawn attention to a neglected but important area of knowledge. To the best of my knowledge, this study appears to be the first of its kind. Literature searches showed that there had not been any previous IPA study published in England on the experiences of Black African service users' recovery from mental illness. Other qualitative studies conducted from the perspectives of BME service users grouped and discussed participants' experiences together regardless of racial and cultural backgrounds and thus failed to make a summative evaluation of BASUs' experiences. The in-depth exploration of the participants' experiences in this study has demonstrated the value of an idiographic IPA qualitative research methodology, which has allowed the voices of Black African service users living in England to be heard. The section below discusses the explanatory models the participants assigned to their mental illnesses.

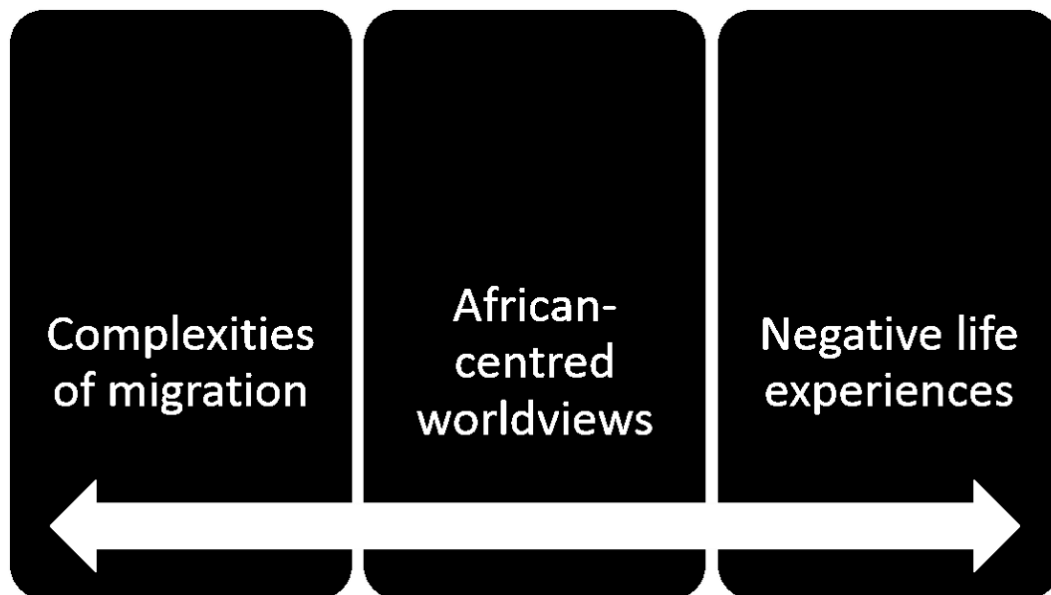
## **7.2 BASUs' Explanatory Models of Mental Illness**

Findings from the present research demonstrated that participants attributed the causes of their mental illnesses to the complexities of migration, African-centred worldviews and negative life experiences. These are illustrated in Figure 2, a conceptual framework displaying

the three explanatory models of mental illness that emerged from the study as separate but inter-connected blocks.

Consistent with the literature, the findings revealed a strong link between migration and mental illness (Bhugra, 2004; Cantor-Graae and Selten, 2005; Cantor-Graae et al., 2003; Dealberto, 2010; Selten et al., 2005; Zolkowska et al., 2001). As demonstrated in the findings, many of the participants gave detailed narratives of their experiences of migration trajectories to England that were consonant with the three stages of migration described by Bhugra and Jones (2010): (i) pre-migration or deciding and planning the migration; (ii) the actual migration; and (iii) the post-migration stage that involves adaptation to the socio-cultural lifestyle of the new society.

**Figure 3: Participants' explanatory models of mental illness**



### **7.2.1 Complexities of Migration**

Bhugra and Jones (2010) explain that the concomitant tensions of culture shock,

acculturation, assimilation and deculturation can bring untold stress onto the immigrant, which can broadly contribute to mental illness. Many participants spoke about their struggles to adjust to life in England, which often triggered nostalgic feelings and longing for their native countries as the beginning of their mental illness.

It has been suggested that problems with acculturation can expose some immigrants to vulnerabilities, especially when confronted with the need to integrate into the dominant culture (Bhugra et al., 2010); such psychological conflict can result in a divided self and a disjointed person (Park, 1928). There were powerful narratives from the participants indicating an increase in alcohol and illicit drug use, aggressive behaviours, stress and suicidal thoughts precipitated by stress of acculturation and adaptation.

A model by Berry (2007) describes the four basic outcomes of acculturation and assimilation: integration, assimilation, separation and marginalisation; these can provide an important context for this research. From a mental health perspective, Berry (2007) argues that the ideals of multiculturalism or integration with the host country whilst keeping ties with the home culture are the best outcome. Those rejecting the host country's lifestyle whilst simultaneously isolating themselves from their own community are likely to become alienated, lonely and marginalised and thus they may become distrustful and paranoid. People who cling to their culture, traditions and community and refuse to adapt to the host country's way of life are likely to confine themselves to small communities and develop confused identities. Nonetheless, those who fully assimilate into the host country's culture are likely to lose their identity, culture and relationships. Relating this to the study, many of the participants who were fully integrated into the English culture whilst simultaneously

maintaining stronger links with their families and social networks reported good progress with their recovery, whilst the opposite was true for participants who were estranged or isolated from their families and social groups.

Providing further context for this study is the seminal work of Krupinski, Stoller and Wallace (1973). The authors' inquiry into the mental health of refugees after the Second World War showed a link between experiences of war trauma and psychiatric breakdown. Relating this to the study, many of the participants reported that they came to England as refugees fleeing wars and traumatic experiences such as physical and psychological abuse, political persecution etc. For example, Winter et al. (2016) recently explored the background context to the Sierra Leone civil war, recounting the stories of survivors, including former child soldiers, amputee footballers, mental health service users and refugees, and issues about post-traumatic stress and post-traumatic growth and resilience. The legacy of pre-migration factors such as wars, political persecution, human rights abuses and poverty provided a backdrop for their vulnerabilities.

### **7.2.2 African-centred Spirituality and Worldviews**

The narratives of the participants demonstrated that their complex perceptions of mental illness were influenced by their African-centred spirituality or African-derived cultures or worldviews. This is consonant with the suggestion that cultural contexts and beliefs are often used by people to explain their distress (Bracken and Thomas, 2005; Kleinman, 1988; Weiss, 1997; Williams and Healy, 2001). It was revealed in the findings that, at first, most of the participants felt that their mental illnesses were caused by an evil spirit, witchcraft, sorcery, magic or mystical powers. This is consistent with a study by McCabe and Priebe (2004) that

found that some Africans are more likely to cite spiritual explanatory models as the cause of their mental illness. Reinforcing the above is the fundamental belief in the traditional African worldview that the world is filled with malicious and unpredictable supernatural powers; staying on good terms with these forces is considered to be essential for a person to continue to enjoy a happy and successful life (Turaki, 2006). Furthermore, the finding that participants believe their mental illness is caused by mystical or supernatural powers is supported by Patel (1995) who finds that spiritual explanations are often cited as the causes of mental illness in many Sub-Saharan African countries. Studies examining concepts of mental illness in Sub-Saharan Africa such as Abbo et al. (2008) in Uganda; Ventevogel et al. (2013) in Burundi, South Sudan, and the Democratic Republic of Congo; Mzimkulu and Simbayi (2006) in South African; Olugbile et al. (2009) in Nigeria; and Muga and Jenkins (2008) in Kenya have largely found that supernatural powers, witchcraft, spirit possession and angered ancestors are often attributed as the causes of mental illness.

Narratives from participants also revealed that at the onset of mental illness, explanatory models were fragmented and complex, but these were readily discarded after gaining some insight. Similarly, research on people presenting with mental illness for the first time revealed that their various explanatory models were incoherent and immediately dismissed (Bhugra, 2005).

### **7.2.3 Negative Life Experiences**

Findings demonstrated that many participants experienced post-migration negative experiences such as immigration restrictions, inadequate access to health, education and employment, and negative reactions from the English societies, which adversely affected

their mental health and recovery. Such negative experiences echoes research findings by Lindencrona, Ekblad and Hauf (2008) that reveals that marginalisation, social oppression, discrimination, restricted employment opportunities and lack of social support can contribute to mental illness in many immigrants. The findings are also consistent with recent studies that have found that stigma and discrimination continue to undermine the recovery of many service users (Knifton, 2012; Knifton et al., 2010; Zhang et al., 2017). A recent study by Whitley (2016) finds that stigma and financial stress are major barriers to recovery for many ethnic minority service users, whilst employment and social involvement are cited as facilitators of recovery. The following section discusses the components of recovery that emerged from the present study.

### **7.3 Components of Recovery**

The findings from the present study revealed that many of the participants conceptualised recovery in the context of their social and cultural backgrounds, remission or eradication of symptoms, spirituality and supernatural powers, usefulness in society, ability to bounce back, and unique personal identities. This is illustrated in Figure 3, where a recovery model is depicted as a bubble encapsulating the six components of recovery – socio-centric or collectivist, clinical, spiritual, functional, resilience and identity – that emerged from the research.

The complex process of contextualising recovery by the participants meant that some of the factors were closely linked and overlapped with one another, whilst some emerged as continuums. A summary of the recovery model is presented in Table 6, which also lists the six components, the details of encompassing factors, the various agents involved and the

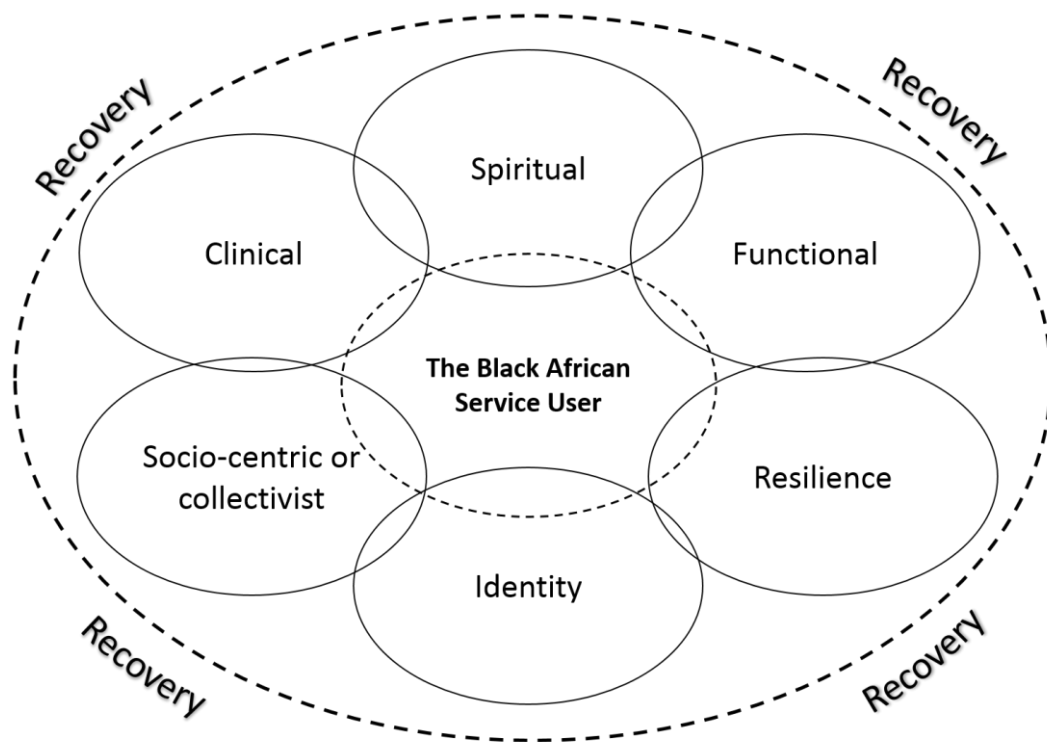


expected outcomes.

### **7.3.1 Socio-centric or Collectivist Recovery**

The current study found that participants largely conceptualised recovery as a socio-centric or collectivist process (Bhugra, 2005; Kusserow, 1999). This finding is contrary to previous studies which have suggested that the Western concept of recovery is egocentric or individualistic (Adeponle et al., 2012; Bhugra, 2005). In distinguishing the dichotomy between individualistic and collectivist cultures, Hofstede (1980; 1984) explains that the individualistic culture is one where relationships are loose and emphasis is placed on individuals and their immediate families, whilst collectivist societies live in a more integrated and cohesive group where kinship, collective identity, emotional interdependence, group solidarity and group decisions are highly valued. The findings in this study revealed that many of the participants felt their recovery would not be possible without their families and social circles. Thus, many contextualised their experiences against the backdrop of their connections with families and communities at large. This deep sense of strong mutual interdependence is consistent with the writings of prominent African philosophers who have championed the idea that the African conceptualisation of personhood is embedded in communalism to help the individual to achieve well-being and realise selfhood (Gyekye, 1997; Mbiti, 1990; Menkiti, 1984; Wiredu, 1996).

**Figure 4: The emergent model of recovery**



In many African societies, the uniqueness of the individual is not rejected, but the notion that an individual can be understood separately from his or her social group is rejected (Scheile, 2015). The individual is regarded as part of a family that belongs to an extended family (Mbiti, 1990), and the extended family is the justification for social co-operation, responsibility, and security (Ayisi, 1992). Thus, community belongingness is said to be the single most highly valued tradition in Africa. The essence of this is captured in a proverb: 'I am because we are and because we are therefore I am' (Mbiti, 1990, p.141). Many of the participants' narratives reflected the above.

Findings from the current study could also be related to many Western studies that

championed the importance of social support and networks to recovery (Borg and Davidson, 2008; Pernice-Duca and Onaga, 2009; Armour et al., 2009; Schön et al., 2009; Sheridan et al., 2014; Tew et al., 2011). However, the findings revealed that many of the participants' worries were compounded by negative attitudes and stigma stemming from their own family members and social networks, which adversely affected their recovery journeys. In this regard, Menkiti's (1984) analysis of personhood in the African context is useful as a framework to examine the participants' negative social experiences. According to this author, the notion of personhood is not given by right in many African cultures, but it is either earned or sanctioned socially. This is because there is a profound belief in many African societies that individuals can be incompetent, ineffective, or fail in personhood (Menkiti, 1984). This might be the reason why many participants suggested in their narratives that they had failed in life and lost dignity in the eyes of their families and social networks.

### **7.3.2 Clinical Recovery**

Findings from the current study revealed that recovery was conceptualised as a clinical outcome and expressed as a continuum, where on the one hand some participants spoke about the concept in relation to reduction of symptoms or return to a former self, as illuminated by, for example, Bellack (2006); Davidson and Roe (2007); Liberman et al. (2002); Slade (2009); Silverstein and Bellack (2008); and Whitley and Drake (2010). On the other hand, many of the participants conceptualised clinical recovery in the context of finding effective medication. A similar outcome has been reported by many authors like Sveldberg, Backenroth-Ohsako and Lutzen, (2003); Piat and Sabetti (2009); and Whitley and Drake (2010).

However, consonant with the literature (i.e. Bizub, 2013; Piat and Sabetti, 2009), many participants reported mixed feelings with regard to medication, mainly due to debilitating side-effects, feelings of disempowerment and perceptions of being coerced to take medication in restrictive environments. Despite the negative views about medication, there were powerful narratives from the participants indicating that non-compliance with medication would lead to relapse and readmission to hospital. Thus, many participants had sought alternative treatments via the African traditional medicine, faith-based organisations, prayers, deliverance and anointment.

### **7.3.3 Spiritual Recovery**

Findings demonstrated that participants collectively acknowledged that their faith, religion and spirituality could inspire positive effects and general wellbeing. Substantial empirical evidence has shown the positive impacts of spirituality and religion on health in general (George, Ellison and Larson, 2002), as well as on mental health (Bussema and Bussema, 2007; Dein and Cook, 2015; Dein and Littlewood, 2007; Fallot, 2007; Huguelet et al., 2016; Ho et al., 2016; Mohr et al., 2006; Siddle et al., 2002; Whitley, 2011). Moreover, the study echoes the findings by Leamy et al. (2011) that suggest people of Black descent place greater emphasis on spirituality in their understanding of recovery. Likewise, both Mbiti (1990) and Turaki (2006) have suggested that religion is quintessential to many African people.

Many of the participants were optimistic that their relationship with a supreme being meant that their wishes to recover would be answered. Such a belief system is consistent with Turaki's (2006) suggestion that the African belief systems are pragmatic, existential and experiential. The author further suggests that religion and spirituality are used as hope-

inspiring factors to meet people's needs and wishes. However, it was also evident from the findings that many of the participants' religious beliefs had negative effects on recovery. This is consistent with many empirical studies that have reported a link between negative effects of spirituality and religion and mental illness (Bussema and Bussema, 2007; Dein and Cook, 2015; Siddle et al., 2002).

#### **7.3.4 Functional Recovery**

Findings from the current study revealed that loneliness, isolation and unemployment had significant adverse effects on the participants' recovery. Many participants expressed their wish to be part of the larger community and become resourceful persons. This is consistent with previous empirical studies such as Chesters et al. (2005); Mezzina et al. (2006); Onken et al. (2007); Perese (2007); and Borg and Davidson (2008) who have found that recovery unfolds in the context of social involvement. It has also been suggested that supportive environments, social connectedness and belongingness are important facets of recovery (Browne et al., 2008; Connell, King and Crowe, 2011; De Silva et al., 2005; Gutman et al., 2009; Mezzina et al., 2006; Naslund et al., 2016; Smyth, Harries and Dorer, 2011; Van Lith, Fenner and Schofield, 2011).

It was revealed in the findings that participants placed emphasis on employment, personal achievement, education and housing. Studies have shown that providing employment opportunities (Biringer et al., 2016; Borg and Davidson, 2008; Burns et al., 2007; Doroud, Fossey and Fortune, 2015; Gilbert et al., 2013; Markowitz, 2015), education and employment (Mowbray et al., 2005; Rudnick et al., 2013) and secure accommodation (Browne and Courtney, 2005a and 2005b; Browne, Hemsley and Courtney, 2008; Chesters et al., 2005;

Whitley, Harris and Drake, 2008) are important impetuses for recovery. Some of the participants' strong desire to be successful in life resonates with Akyeampong (2000) who suggests that for many Africans, the diaspora is an important geographical location to improve themselves and overcome the accumulative social liabilities.

#### **7.4 Resilience**

The findings demonstrated that even though many participants were 'shattered' by their experiences of mental illness and the connected problems that came with it, many drew upon their internal and external strengths, positive attitudes, optimism, pragmatism, self-efficacy, sense of humour, social skills and spirituality to thrive. This suggests that resilience prevailed in various degrees for many of the participants. This is consistent with previous qualitative studies that have demonstrated that resilience can lead to adaptation, self-awareness, hope and optimism (Edward, 2005; Edward, Welch and Chater, 2009; Kalathil, 2011). These studies further suggest that resilience can lead to understanding, change in attitude, growth and a new sense of identity. It was evident in the participants' narratives that their resilience had paved the way to acceptance of their diagnosis and eventual recovery.

In this research, participants demonstrated that being resilient meant accepting their mental illness and moving on with their lives. Studies have shown that learning to accept mental illness and the concomitant difficulties are key precursors to recovery (Ajayi et al., 2009; Andresen et al., 2003; Bowyer et al., 2010; Edward et al., 2009; Repper and Perkins, 2003). Rutter (2006) finds five main characteristics of resilience emerging from the literature: first, the notion of resilience can be seen as exposure to risk, as opposed to its avoidance; second, resilience arises from the developing resistance to the experience of stress or adversity; third,

resilience entails physiological and psychological coping strategies; fourth, resilience sometimes ensues at a decisive period long after the adverse experience; and fifth, resilience may be hindered by psychopathological factors or by the negative effects of stress/adversity on the nervous system. The narratives revealed that after heart-breaking negative experiences in many of the participants' lives, many became more resolute than ever to overcome their difficulties. This was dependent on their self-efficacy or physiological and psychological adaptations, as well as a mixture of support from social circles and professionals.

Gunnestad (2006) also suggests that culture is the lifeblood of resilience. As demonstrated in the findings, the participants drew on their socio-cultural contexts to make sense of their experiences. Their narratives fitted well with several resilience theories. Three theories in particular – metatheory of resilience and resiliency (Richardson et al., 1990; Richardson, 2002); the Ecological Transactional Model (Cicchetti and Lynch, 1993); and resilience as homeostasis (O'Leary and Ickovics, 1995) – are drawn on to elucidate the participants' experiences of mental illness and recovery. The rationale for choosing these theories is that they are culturally relevant constructs (Southwick et al., 2014) and holistic in their approach.

First, Richardson et al. (1990) and Richardson (2002) present the metatheory of resilience and resiliency as three interconnected concepts – body, mind and spirit or biopsychospiritual balance (homeostasis) – that facilitate our ability to adapt positively to adverse life events. The main idea behind the theory is an examination of the relationships between everyday stressors and protective factors to determine whether adverse life events will have a severe and chronic effect on individuals. The theory proposes that people's ability to adapt and cope

with adversity is largely influenced by resilient qualities and prior resilient reintegration. The theory fits well with the participants' experiences. As evident from the findings, some participants narrated how they overcame adversity in their native countries before coming to England, and when faced with various bio-psychosocial problems in England, they utilised their existing resilient skills to deal with their problems.

Second, Cicchetti and Lynch (1993) propose an ecological transactional model which is conceptualised as existing in a multilevel environment (macrosystem, exosystem, microsystem and ontogenic) for the individual. The macrosystem is conceptualised as cultural beliefs and values that permeate societal and family functioning; the exosystem is the neighbourhood and community settings; the microsystem is the family environmental experience; and the level of ontogenic development is expounded as the developmental adaptation. According to Cicchetti and Lynch (1993), these levels of the environment constantly interact and transact with each other, contributing to shaping the development and adaptation of the person. As presented in the findings, in the face of adversity many of the participants utilised their socio-cultural connectedness, sense of identity, self-efficacy and adaptive coping strategies to navigate many of the difficulties they were experiencing.

Finally, in the resilience as homeostasis theory, O'Leary and Ickovics (1995) propose that when people are confronted with crisis they are likely to respond in one of four possible ways: succumb, survive, recover or thrive. The authors suggest that succumb corresponds to deterioration of everyday functioning after a crisis. Survival suggests a possible impairment, but some level of functioning after a crisis. Recovery refers to the ability to bounce back to the level of functioning before a crisis, and thriving suggests a return to the former level of



functioning after a crisis, or even growing or flourishing to a level that surpasses the level of functioning before the crisis. The resilience as homeostasis theory resonates with the experiences of many of the participants in this study, as their narratives were suffused with illustrations of experiences ranging from hopelessness to transformative feelings of recovery and beyond. Despite myriad problems and setbacks, many of the participants showed in their narratives that they had the capacity to adapt, recover and transition to new life challenges. Such experiences are also consistent with Yehuda et al. (2006), who suggest that exposure to adversity does not automatically lead to the development of dysfunctional behaviours.

### **7.5 Identity**

As indicated in the prologue and the inclusion and exclusion criteria (section 3.1), the participants' perceptions of their identities were central to the research project. Equally, many of the participants mentioned that their Sub-Saharan African ethnicity, communal and tribal belongingness were critical to their emotional wellbeing (Ahmed, 2007) and recovery journeys. This is consistent with many developmental and social psychologists who have suggested that ethnic identity is one of the most important facets of people's self-concept and identity (Sellers et al., 1998; Yip, Seaton and Sellers, 2006).

Three seminal theoretical frameworks examining identity were identified as important to the study: theory of identity development (Erikson, 1968); developmental models of ethnic identity (Marcia, 1966; 1980); and ethnic identity development (Phinney, 1989; 1990; 1993). Of these theoretical underpinnings, arguably the most relevant, the ethnic identity development by Phinney, is drawn upon to illuminate the identity formation of the participants.

Phinney (1989; 1990; 1993) assumes that individuals in all ethnic groups progress through three stages: (1) unexamined ethnic identity entailing people's unexamined positive or negative views of their ethnic group; (2) ethnic identity search or exploration of what it means to belong to a group; and (3) achieved ethnic identity signifying end of exploration and clear understanding of ethnicity. Whilst a feeling of positive affection from belonging to an ethnic group is not addressed in the model, Phinney (1992) later argues that ethnic identity and belongingness can trigger a positive sense of self for many individuals. Putting Phinney's (1989; 1990; 1993) theory into the context of this research, the participants' narratives suggested that the identity question of who is an African is far more complex than mere self-perceptions. There were several instances where participants expressed either positive or negative views or both about their African identity. Moreover, a few appeared bewildered and suggested that they were in the middle of two worlds between Africa and England and were still searching for their true identity. This was also a determinant of how the participants embraced or struggled with adaptation, assimilation and acculturation.

Whilst many participants asserted their inescapable sense of pride in being African, others contextualised that the services undervalued their identities as Africans. Social identity theorists Tajfel and Turner (1986) have outlined three strategies by which individuals from undervalued groups negotiate their identities: first, individual mobility: physically or psychologically leaving the group. Second, social creativity or collective redefinition or re-examination of the group ideals: this involves constant comparison with other groups perceived as superior, with a view to changing the image of the group from negative to positive. Third, social competition: the group fights the current system in the hope of changing

the standing of the group members in society. Narratives from the participants revealed that, whilst few readily disassociated themselves physically and psychologically from their social groups, others were idealistic about improving their image as Africans or even rebelling against the mental health and civic systems for improved services.

## **7.6 Experiences with the Mental Health Services**

Disengagement and compulsory detention were often described as two ends of the same spectrum in the participants' experiences with services. It was apparent from the narratives that almost all the participants accessed the mental health services via crisis routes and the Mental Health Act 1983. Most participants spoke about their reluctance to seek help at the onset of their mental illness because of fear and mistrust of the services. Studies have found that the major reasons for higher rates of detention among Black people in England are unwillingness to seek help in times of crisis (Cooper et al., 2013; Lawlor et al., 2012), and disengagement due to negative experiences (Fearon et al., 2006; Littlewoods and Lipsedge, 1997). Swartz et al. (2003) find that fear of coercive treatment is one of the main reasons for reluctance to seek help. The link between Black service users and compulsory detention was recently confirmed in a study by Gajwani et al. (2016). Furthermore, statistics show that in 2012/13, around 70% of mental health service users of Black origin were subjected to compulsory detention (Health and Social Care Information Centre, 2013). Surveys (Care Quality Commission, 2010) and systematic reviews (Bhui et al., 2003; Singh et al., 2007) have found that pathways to mental health services for Black service users often involve crisis routes and higher than average compulsory detention rates.

The findings revealed that most participants were given a primary diagnosis of schizophrenia

or psychosis on their first contact with the services. A considerable amount of literature has been published reporting a greater incidence of first-episode psychosis (Mann et al., 2014) and severe and enduring mental health disorders (Singh et al., 2014) amongst service users of African origin. A study in three major urban areas in England finds that Black Africans are at a six-fold risk of being diagnosed with schizophrenia in comparison to the White British population (Fearon et al., 2006). However, studies have reported that once variable factors such as age, gender, diagnosis, risk and pathways to care are controlled, the notion of excessive compulsory admission for BME service users becomes trivial or widely baseless (Corrigall and Bhugra, 2013; Lawlor et al., 2012; Singh et al., 2014; Singh et al., 2007).

Despite the fact that many of the participants were sectioned on first contact with the mental health services, as well as being given a diagnosis of serious and enduring mental illness, few expressed dissatisfaction with the services and the majority overwhelmingly expressed content with the service experience. It has been suggested that many service users retrospectively find compulsory detention unbeneficial and unjustifiable (Katsakou and Priebe, 2006; Priebe et al., 2010; Priebe et al., 2009). This does not appear to be the case for most of the participants in the present study. Many retrospectively mentioned that they understood and accepted why they had been admitted against their will and they found the compulsory admission enlightening. This is supported by quantitative research that reports mixed findings on service users' attitudes towards compulsory detention. For example, Katsakou et al. (2011) note that some of their participants were either ambivalent about their compulsory detention or felt that it was wrong or right. Rooney et al. (1996) suggest that many detained patients were initially less positive about their admission to hospital, but they

became more positive after discharge. Other quantitative researches have generally found that most service users are satisfied with compulsory detention (Adams and Hafner, 1991; Gove and Fain, 1973; Toews et al., 1986).

Many participants recounted their positive experiences with professionals and the important role they played in their recovery. Studies have shown that by connecting and forming trusting relationships with professionals, service users strengthen their identity, hope and optimism, and recovery (Eriksen et al., 2014; Leamy et al., 2011; Topor et al., 2006). However, a few participants felt that they would have a more positive experience if professionals understood their experiences as Black Africans. Despite this, many dismissed the idea that assigning or matching Black African staff to their care would guarantee empathy and understanding (Secker and Harding, 2002).

**Table 6: Components of recovery**

Components	Encompassing factors	Agents involved	Outcomes
Socio-centric/collectivism	Communal belongingness Group solidarity Cultural heritage (beliefs, norms and values)	Family Friends Community: local/tribal/fellow country members Mental health clinicians	Emotional interdependence (Hofstede, 1980; 1984) Kinship (Hofstede, 1980; 1984) Emotional sustenance (Ahmed, 2007) Loyalty and obligation Social support
Clinical	Orthodox medication Traditional African medication	Psychiatrists GPs Mental health nurses Clinical psychologists	Cure Eradication of symptoms Reduction of symptoms Feelings of disempowerment Perceptions of coercion
Spiritual	Religion Christian faith Church Prayers Traditional religion/belief Songs and religious ceremonies Anointing	A supreme being (God) Holy Spirit Supernatural powers Impersonal powers Witchcraft Family Friends	Salvation (Kunhiyop, 1997) Exorcism (Kato, 1975) Hope and optimism Emotional well-being Sense of self-efficacy and autonomy Sense of empowerment Quick answers (Turaki, 2006) Cleansing of sins (Turaki, 2006) Fundamental psychological belief (i.e. fear of spiritual powers; lack of consolation, peace and comfort; little distinction between good and evil; fatalism; pursuit of spiritual power (Turaki, 2006))

Functional	Employment Education Housing	Local council Housing associations Colleges Higher institutions Immigration authorities	Secure employment Secure housing Vocational qualification Apprenticeship
Resilience	Exposure to adversity/stressful events Migration Emotional regulation Positive self-perception	Family Friends Community Mental health clinicians	Change or stress becomes a challenge/opportunity; commitment (Kobasa, 1979). Self-efficacy; realistic sense of control, sense of humour; adaptability to change (Rutter, 1985). Patience; tolerance of negative affect (Lyons, 1991). Optimism; faith (Connor and Davidson, 2003).
Identity	Sub-Saharan African ethnicity Communal belongingness Migration Cultural identity (language, family customs, country of origin, religious and political beliefs, gender)	Family Friends Community: local/tribal/fellow country members	Emotional sustenance (Ahmed, 2007) Strong racial, ethnic and cultural identities. Struggle with or embrace culture shock, adaptation, assimilation, acculturation and deculturation (Bhugra and Jones, 2010). Loss of identity Loss of personhood Existential threat Disempowerment

## **7.7 Limitations of the Study**

There were a few limitations to the study. First, as discussed in the reflexive chapter (Chapter Eight), as a Black African I was potentially treated as an insider by many of the participants and this may have in fact motivated participants to agree to take part in the study. However, as specified in the participant information sheet, participation in the research was entirely voluntary and it did not affect current or future care in the NHS. Participants were also advised in the participant information sheet and during the interviews that they were free to withdraw at any time and without providing an explanation.

Second, IPA positions itself as an interpretive endeavour. Therefore, making sense of the participants' experiences required a level of interpretation. Despite being reflective throughout the course of the research, it is possible that my preconceived ideas emerging from my identity as a Black African and my background as a mental health practitioner may have impacted on the interpretation of the data. However, in order to ensure the validity and quality of the entire research process, reasonable steps were taken to minimise personal impact on the quality of the results. Nonetheless, there is a possibility that interpretation by other researchers would produce different results.

Third, congruent with IPA, the data for this study was obtained from a relatively small sample that is not representative. Therefore, typical criticisms of qualitative research are also applicable here: the findings from this study can be considered subjective, not generalisable, and not reliable and replicable (Yardley, 2000). However, as Yardley points out, the qualitative research approach avoids rigid evaluations and embraces many possible interpretations of a phenomenon. Furthermore, generalisability of findings has never been the aim of IPA. In



accordance with the subjective nature of the issue and interpretation of the data, I invite the readers to judge the generalisability of this study based on their own experience.

Finally, from the outset of this research I have argued that conceptualisation of recovery is predominantly Eurocentric and have advocated a conceptualisation that sufficiently takes the unique socio-cultural contexts of Black Africans into consideration. However, the inherent limitation of this study is the use of IPA, which is a conceptualisation of Western philosophy and is arguably alien and incompatible with most traditional African cultures. Nevertheless, I took reassurance from the fact that IPA research is said to be about inquiry into the socio-cultural meanings of individuals (Smith et al., 2009).

## **7.8 Clinical Implications**

There are clinical implications from this research especially in relation to current and future provision of care and promotion of recovery for Black African service users in England.

First, given that the participants defined recovery as a pragmatic and subjective concept distributed across a continuum of clinical, functional, spiritual, resilience, identity, and communal belongingness, it seems critical for mental health service providers and clinicians to ensure that these components are embedded in recovery-oriented services. The emergent model of recovery (figure 4) could be adopted to augment recovery-oriented practice for BASUs. Evidence suggests that supporting personally defined recovery enhances working and therapeutic relationships with service users (Le Boutillier et al., 2011).

Second, the study raises important reflections for clinical practice regarding the roles of religion and spirituality in promoting recovery for black African service users in England. It is encouraging to note that participants freely articulated the complexities of their religiosity.

However, we must concede that their narratives also suggest that the black African sense about the causes of mental illness and recovery are significantly different from the Western perspective. In their analysis of the current issues about the relationships between religion and spirituality and mental illness, Dein et al. (2012) highlighted that certain ideologies and rituals vary across cultures and religion and this translates into coping mechanisms. A case in point, Africans uphold their traditional beliefs and culture on becoming Christians (Turaki, 2006), and most practice a Pentecostal and pragmatic faith filled with emphasis on spiritual gifts such as speaking in tongues, divine healing, and prophecy (Dein and Littlewood, 2007). Though not exclusively unique to Africans, but as a black African, I am too familiar with the traditional African style of worship and its hallmark of energetic clapping, dancing, singing, praying, speaking in tongues, and giving prophecies. These attributes sharply differ from the Western style of worship typically marked by solemn singing of hymns and quiet recitation of prayers. If all the NHS inpatient hospitals are expected to cater for the dietary needs of people from diverse cultural backgrounds and provide for example, kosher, halal, vegetarian, or vegan foods for Jewish, Muslim, and vegetarian service users respectively; then I would argue that the religious and spiritual needs of black African service users must be given equal priority. A sympathetic approach for example, for future inpatient mental health services is to consider the diversity of culture and ethnicity and provide dedicated areas for black African service users overwhelmed with mental illnesses to practice their religion vociferously and freely without being labelled as 'floridly psychotic' or 'responding to external and unseen stimuli'.

Third, through their narratives, participants expressed that their experiences of mental illness and recovery were embedded within their social and cultural contexts. Therefore, by understanding the stories behind these experiences, services can also begin to make sense of them and create a shared understanding, assessment, diagnostic criteria and services to meet BASUs' recovery journey.

Finally, participants reported that the involvement of their families and social networks formed an important impetus in their recovery journeys. It would therefore make sense for services to consider the people in the individual's wider social network when planning care and interventions.

### **7.9 Suggestions for Future Research**

The current study has highlighted the need for further exploration of BASUs' experiences of mental illness and recovery using methodologies reflecting their own cultural worldviews and heritage of the African culture (Asante, 2007). Findings from this study demonstrated that the participants' families and social networks were a important recovery impetus. Therefore, exploring the views of families and social networks with regard to BASUs' experiences would be an important next step.

The participants were from different African countries and cultural backgrounds. Further exploration of the lived experiences of BASUs in England in relation to specific African countries, regions or cultures would contribute to a more nuanced and rounded understanding of BASUs' experiences with mental illness and recovery from mental illness.

Findings from this study revealed that the concept of resilience has the potential to be a

potent force in recovery. Therefore, further exploration into the resilient factors of BASUs in relation to recovery would be an important next step.

### **7.10 Summary**

This chapter has presented the key understandings and contributions emerging from this study, as well as implications for clinical practice. Through their narratives, participants told complex stories about their experiences of recovery from mental illness in England. This study adds to the existing knowledge and provides greater understanding about the lived experiences of BASUs.

## CHAPTER EIGHT: REFLEXIVITY ISSUES

### 8.0 Introduction

My interest in the research topic was inspired by my experience of working with a black African service user from Sub-Saharan Africa. I was captivated by his experiences, which were submersed by a myriad complex issue, including negative perceptions of and discrimination in the English mental health system. As a black African, I was overwhelmed by his experiences. I also identified with them: I have had my own negative experiences in both my personal and professional life in England.

For example, I have been humiliated by some service users, taunted and told to 'speak proper English', because they found my accent amusing and unintelligible. I have been bullied and unjustly criticised in my clinical work, compounding my emotional distress as an immigrant in England. My professional education and family support have made me strong and resilient. However, my experience does not necessarily generalise to my participants.

I was curious to explore the views of the mental health nursing academic world on the experiences of the service user I encountered.

Given my role as an insider researcher, I will demonstrate how I engaged in reflexivity throughout the study. I began this project with my own personal feelings, interpretations and prejudices. I engaged in reflexivity by keeping a personal research journal from the outset, to note my experiences, feelings, strengths, weaknesses, fears and biases (Braun and Clarke, 2013; Willig, 2008). I also met regularly with my supervisors, which constituted reflexive moments. During these meetings, I reflected on my conceptual understandings, decisions about the research, emerging codes and subsequent themes, and time management. Finally,

I used a few reflection models and frameworks, including the reflective cycle (Gibbs, 1988), reflection-in-action/reflection-on-action Schön (1983) and the experiential learning cycle (Kolb, 1984, 2015) to make sense of my experiences, actions and reactions.

The intent of this chapter is therefore to show transparency and present a detailed and honest account of how my values, experiences, opinions, thoughts, feelings, motivations and constraints have influenced the research process (Braun and Clarke, 2013; Willig, 2008). The next section discusses the concepts of the insider and outsider researcher, then followed by discussions about the complexities of my insider role in relation to the research site, the participants and data analysis. I support my reflections with extracts from my research journal.

### **8.1 The Insider/Outsider Researcher**

The issue of insider/outsider received increasing attention in empirical research in the twentieth century. Mercer (2007) traces the roots of the concept of the insider/outsider researcher to a number of White anthropologists who, at the turn of the twentieth century, conducted extensive research on 'exotic' natives and cultures. The noticeable differences between the researchers and the researched natives ultimately led to the construction of the outsider researcher. Then, in the second half of the twentieth century, researchers began to shift their focus of research onto familiar cultures. Thus, based on the premise that some groups have privileged and unfettered access to certain kinds of culture and knowledge, the concept of the insider researcher emerged (Mercer, 2007). Merton (1978) suggests that insider researchers belong to specified social groups or occupy distinguished social statuses with access to privileges that outsider researchers do not enjoy. Griffith (1998) states that the

insider researcher shares characteristics with the group being studied, such as experience, gender, race, ethnicity etc. By contrast, the outsider researcher does not share any commonality with the group being studied.

However, some authors reject this simplistic view and instead suggest a continuum or a buffer zone where the researcher can occupy both positions (Acker, 2000; Deutsch, 1981; Dwyer and Buckle, 2009; Griffith, 1998; Mercer, 2007). For example, as outlined below (section 8.5), I noticed a great deal of 'slippage and fluidity' between my insider-ness and outsider-ness (Meriam et al., 2001, p.405) during data collection. However, the purpose of this chapter is not to discuss the debate between the insider/outsider researcher as this issue cannot be fully resolved (Acker, 2000); instead, my aim is to proclaim and explore the complexities of my insider role during the research.

## **8.2 My Double Insider-ness**

My personal and professional identities meant that I occupied dual insider roles during the research. First, as a Black African and a first-generation African immigrant, I shared a similar racial and immigration experience to most of the participants. I also shared commonalities of Ghanaian nationality, ethnic and cultural understandings and language with two of the participants. It is therefore safe to assume that I would have more in common with immigrants who come from Sub Saharan Africa than, for example, Afro Caribbean immigrants. Second, I am a mental health nurse working at the research site, so as well as expertise and competent knowledge in mental health issues, I also had relatively unconstrained access to the research site. In this study, my multiple insider statuses were noticeable from the onset. Therefore, in the following sections, under the lens of critical reflexivity, I address the

complexities of my insider-ness in relation to the research site, the participants and data analysis.

### **8.3 Complexities of My Insider-ness and the Research Site**

As an insider at the research site, I enjoyed many advantages and disadvantages. To begin with, I had the advantage of easy access to the participants and greater flexibility in data collection (Mercer, 2007). There was also an added advantage of having a great deal of insight about the power and politics existing at the research site (Costley, Geoffrey and Gibbs, 2010; Hannabus, 2000).

However, my insider-ness at the research site was accompanied by the constraints of being entangled in internal politics, conflicts of interest and ethical dilemmas (Costley et al., 2010). For instance, I experienced an ethical dilemma when some staff members spoke to me as a colleague and/or confidant and assumed that they could tell me confidential stories about participants or prospective participants. It often felt as if my roles as a clinician and a researcher were somehow blurred. As Smyth and Holian (2008) suggest, a major risk posed to the credibility of insider researchers is easy access to sensitive information. They therefore recommend the insider researcher to exhibit explicit awareness of any unfairness during data collection and analysis in order to address biases. Thus, throughout the research I used a reflective journal and meetings with my supervisors to reflect on how my insider-ness was affecting the research at various stages.

My connectedness to the research site also exposed me to over-familiarity and what appeared to me as insensitive undermining. To offer an example, many staff members'



attitudes towards me seemed to be patronising and/or negative when I approached them about the research. The only explanation that comes to mind for this is that I was typecast as a mental health nurse and many doubted my credentials as a credible researcher. Costley et al. (2010) point out that insider researchers are likely to face critical colleagues at the research site, and thus professionalism, creativity, ingenuity and ability to negotiate around systems are important to guard against such criticism. I dealt with negative attitudes by applying Kolb's (1984; 2015) experiential learning cycle, which contends that life is full of experiences we can learn from. So, for example, I informally approached and talked to many of my work colleagues to address any questions or queries they had and I took the opportunity to accept appealing suggestions about the research from them.

#### **8.4 Complexities as a Black African Insider**

As a Black African, I believe that I shared various similarities with the participants. Yet, I also believe that the unequal power dynamics between the participants and myself possibly affected the rapport and response during the interviews. Thus, I have been overwhelmed with a series of thoughts about whether the participants responded to me as a mental health nurse or as a fellow Black African with the ability to understand issues affecting their lives. I also wonder whether they saw me as a researcher who was only interested in their stories to get a PhD qualification.

Dwyer and Buckle (2009) suggest that acceptance, trust and openness are some of the benefits an insider researcher enjoys. They contend that participants are more likely to share their experiences with the insider researcher because of the assumption of understanding and distinctiveness. Another advantage is a greater understanding of the culture of the

participants and the ability to capture their unique perspectives and experiences (Bonner and Tolhurst, 2002). However, Dwyer and Buckle (2009) also argue that being an insider researcher could impede the research process. For example, they argue that participants could take assumptions of similarity for granted and fail to provide an in-depth narration of their experiences. The authors also argue that there is a potential that researchers will struggle to bracket off their experiences or preconceptions from those of the participants, and therefore this will affect the interviews and data analysis. In the next section I address the complacencies that accompanied my insider role.

### **8.5 Complacencies about My Perceived Insider-ness**

Serrant-Green (2002) points out that Black people working in Black communities are often erroneously positioned as insiders. I can extend her arguments to my situation and stress that, despite our sameness as Black Africans, participants responded to me differently. A case in point is a situation when my flawed perception of a degree of closeness to the participants led to complacencies, which I became acutely aware of when one of the female participants (Mia) became emotionally distressed a few minutes into the interview and found it hard talking about her experiences. Though it is possible to argue that Mia's withdrawal from the interview was due to personal issues, it could equally be suggested that my naivety in going into the interview contributed to her breakdown, as I believed that I was automatically an insider by being a Black African and I would therefore easily establish a rapport with all the participants. My preconceptions were reversed when Mia reacted to the interview emotionally. Perhaps an alternative explanation to her breakdown is that she found it upsetting talking about sensitive issues in her life with a male. As Tannen (1992) suggests,

even in a shared socio-cultural context there is a propensity for mixed judgments and misjudgements, especially in a conversation between women and men because of the differences in importance and meanings each gender attaches to experiences.

Having experienced my encounter with Mia, I am convinced that there are no clear advantages to having either insider or outsider status (Mercer, 2007). I also found myself reflecting and asking whether the incident with Mia affected how I handled subsequent interviews. I became very contemplative about whether I held back from asking sensitive questions in subsequent interviews for fear that they might distress the participants. I found Kolb's (1984; 2015) experiential learning cycle and supervision with my supervisors convenient in my preparation for subsequent interviews.

## **8.6 My Multiple Roles**

During the data collection process, I sometimes occupied the multiple roles of a fellow Black African, a researcher, a brother, a compatriot, a sympathiser and a helper. For example, during the interviews, many of the participants referred to me as 'my brother' when recounting their narratives. Many also made comments like 'in our culture', 'you know what I mean', 'you get what I mean', 'back home' when emphasising their point of view. It felt to me that there were special connections and understandings between the participants and myself, and that they were making genuine overtures to connect with me as a fellow Black African and an insider who was interested in their experiences. However, I felt apprehensive about the problem of bias and wrote about this in my reflective journal:

I am a mental health nurse and a Black African interested in the experiences of my participants who are also Black Africans. That means I am not an objective, neutral actor in the research project from the outset. I was the main instrument

of the data collection therefore my socio-cultural background may have affected the outcomes of the interviews. I must confess, I also experience nostalgic feelings when I hear the participants affectionately talking about 'back home'. I have some affinity for the participants when they refer to me as 'my brother'. I am finding the ideals to remain neutral emotionally draining. I am struggling here about the problem of bias in this research [Research Journal, June 2014].

Here, it is evident that at times I struggled to separate my Black African identity and research personas due to the special connection I identified as having with the participants. DeLyser (2001) argues that one of the main problems with being an insider researcher is loss of objectivity. At times, it felt to me that I was immersed in the audacious, melancholic and nostalgic worlds of the participants. However, using Schön's (1983) reflection-in-action/reflection-on-action model I could react to the situation and bracket off any preconceived ideas I was experiencing.

My multiple roles during the research triggered an overwhelming feeling that I was caught up in an ethical dilemma. To illustrate, when I contacted one of the participants (Ama) for the post-interview debrief, she asked if I could help find a job for her husband. I was caught off-guard by her request as I did not have any social connections with her. My initial reaction was that she had had an ulterior motive before agreeing to the interview. I was also contemplative and wondered if I had said anything to Ama that motivated her to approach me with the request. Chavez (2008) has suggested that insider researchers can be overwhelmed by reciprocity requests. However, following my subsequent reflection using Gibbs' (1988) reflective cycle to ponder my feelings and thoughts and evaluate my actions, reactions and inactions, I understood that her request was an 'away from home' factor and a solidarity gesture (Meriam et al., 2001, p.407). I also understood that Ama's request was a common

manifestation amongst immigrants from the same country to network and solicit help and work (Vasta and Kandilige, 2010). Thus, I came to the plausible explanation that Ama was capitalising on our shared commonalities as Ghanaians (with the same culture and native language) to look for a job for her husband.

Despite the suggestions that researchers socially distance themselves from participants and concentrate on the research work (Hammersley and Atkinson, 2007; Victoria, 2011), I could not resist the nobility of giving practical advice to Ama about how her husband could go about applying for a support worker role at the research site. Reflecting on my fraternity with Ama, I considered that I was showing communal belongingness conceptualised in the African traditional thought that 'a person is a person through other persons' (Tutu, 2008). An authoritative conclusion to be drawn from this maxim is the need to strengthen community support, togetherness, empathy, generosity, compassion and sharing (Tutu, 1999), the very qualities I believe I showed to Ama.

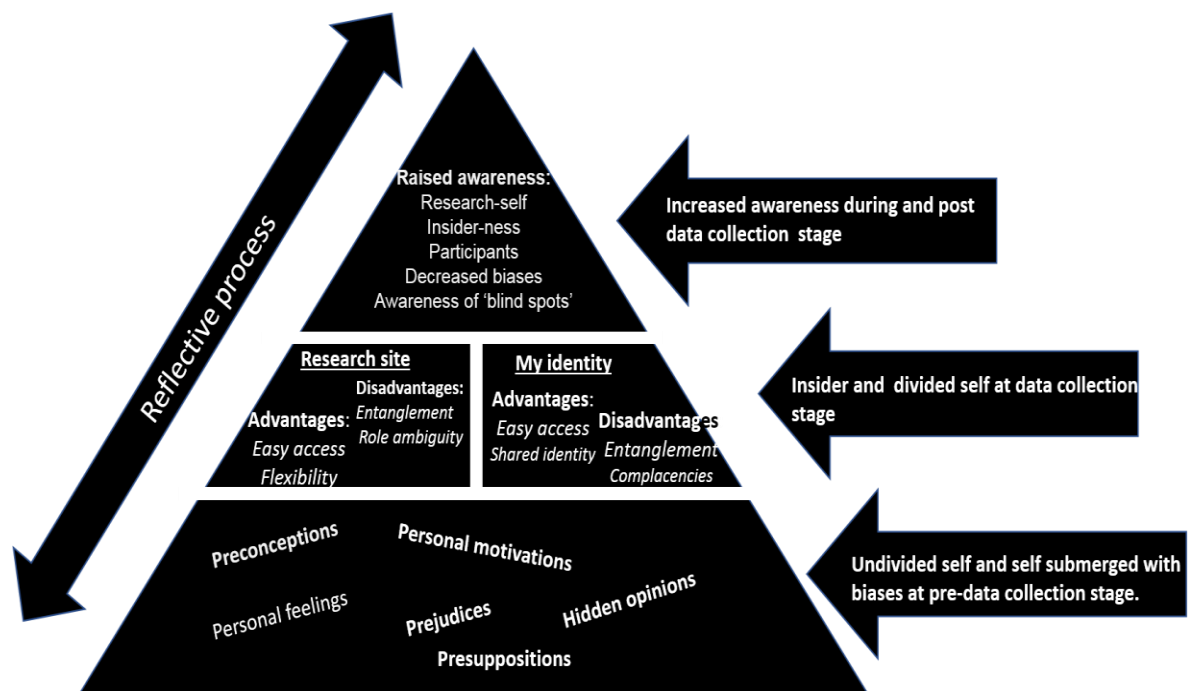
In another incident, I ran into Bobby (another participant) in the town centre several weeks after the interview and he proudly told me that he was now a father. Though our encounter was brief, I was surprised by his warmth and self-disclosure as we had had no further contact after the interview. My impression of this incident was that the interview with Bobby fostered a sense of solidarity and he was trying to connect with me as a fellow Black African to celebrate his milestone. Chavez (2008) suggests that equalised relationship, immediate legitimacy and quick rapport building with the participants are some of the advantages an insider researcher enjoys.

These two incidents led me to deconstruct myself as a serious and worthy researcher who gained the respect and trust of his participants. Arguably, they also help to improve the credibility of the findings. The following is my journal entry after my last interview with a participant:

Apart from the incident with Mia, I found the interview process itself somewhat straightforward. As I listened back to the participant's stories, my life was sometimes engulfed by a tidal wave of sentiments. I sometimes felt shocked or disheartened by their experiences. I realized that I have made personal investment in this project, and I was finding it hard to suspend my own feelings, attitudes, and opinions. However, I am convinced that I was successful at bracketing my preconceptions during the interviews, because I presented myself as a naïve but curious listener who is interested in the participants' world, knowing that the data analysis phase would provide the opportunity for my own detailed and rigorous interpretation and reflections of their account (Smith et al., 2009) [Research Journal, March 2012].

My reflexivity during the entire research process is illustrated in figure 4. Strong preconceptions, biases and hidden prejudices provided the foundation at the beginning of the research project and before I entered the research site to collect data. On entering the research site, I found that I occupied dual insider roles. This came with advantages and complications. Through reflexivity, I could understand my own research persona, my insider-ness and my participants, which ultimately helped to decrease my biases and increase my awareness of 'blind spots' during data interpretation.

Figure 5: Emergent reflective model



## **8.7 Challenges of Data Analysis**

Once I finished transcribing all the interviews, I found myself immersed in the data, reading and re-reading the transcripts to gain a deeper understanding (Smith et al., 2009). As I looked at the rich data, I realised how my careful planning, from the preparation of the interview schedule to conducting the main interviews, had paved the way to the 'construction site of knowledge' (Kvale, 1996, p.2). My priority at this stage was to add human touches and tell a good story with the data (Holloway and Biley, 2011).

As I continued analysis of the data using the idiographic approach required in IPA (Smith et al., 2009; Wilig, 2013), I became acutely aware, through my research supervisors, that I was attuned to certain themes and concepts standing out from earlier transcripts. To illustrate, the complexities of being sectioned and perception of negative treatment in the English mental health system was a major theme for one of the participants (Tina); I found myself constantly identifying issues to do with sectioning and negative treatment experiences in the transcripts of other participants without looking for positive experiences. Drawn to my attention by my supervisors, I began to question whether I was just searching for extracts in subsequent transcripts to strengthen what I had analysed before. I also questioned whether I was able to bracket off any preconceptions I had acquired from the previous interview transcript. It is possible that my perceptions were clouded by acquired preconceptions and therefore this affected the emphasis I gave to some factors in the successive data analysis (Dwyer and Buckle, 2009).

Being an insider researcher is a double-edged sword: on the one hand the researcher may



possess an in-depth knowledge of the culture and unappreciated understanding of the participants, but on the other hand the researcher may fail because of short-sightedness and a missed opportunity to clearly illuminate a phenomenon (Mercer, 2007). IPA research is undoubtedly a personal process requiring subjective interpretation at every stage of the research process (Smith et al., 2009). Thus, my own background and experiences as a Black African and a mental health nurse were required to make sense of the data. I believe that I did my best to present a balanced and coherent analysis to stimulate interest.

## **8.8 Summary**

In this chapter I have undertaken self-reflection as an insider researcher. As a Black African, I enjoyed the privilege of exploring the experiences of my participants. I recognise that I came to the research with many advantages; however, I also experienced several challenges in relation to the research site, data collection and analysis. As I demonstrate throughout this chapter, reflexivity is an important safeguard for minimising ethical dilemmas.

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## APPENDICES

### Appendix 1 - Favourable ethical opinion letter from the NHS Local Research Ethics Committee (LREC)



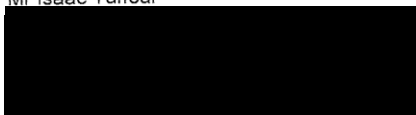
#### National Research Ethics Service

Berkshire Research Ethics Committee

Telephone: [REDACTED]  
Facsimile: [REDACTED]

10 August 2010

Mr Isaac Tuffour



Dear Mr Tuffour

**Study Title:** Black African Service Users (BASUs) Experience of the Recovery Approach in Mental Health Provision in England.  
**REC reference number:** 10/H0505/46  
**Protocol number:** 2

Thank you for your letter of 20 July 2010, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information was considered in correspondence by a sub-committee of the REC at a meeting held on 4<sup>th</sup> August 2010. A list of the sub-committee members is attached.

#### Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

#### Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

#### Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

For NHS research sites only, management permission for research ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research

This Research Ethics Committee is an advisory committee to South Central Strategic Health Authority

*The National Research Ethics Service (NRES) represents the NRES Directorate within the National Patient Safety Agency and Research Ethics Committees in England*

- Notifying substantial amendments
- Adding new sites and investigators
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email [referencegroup@nres.npsa.nhs.uk](mailto:referencegroup@nres.npsa.nhs.uk)

10/H0505/46

Please quote this number on all correspondence

Yours sincerely



**Professor Nigel Wellman**  
Chair

Email:



Enclosures: List of names and professions of members who were present at the meeting and those who submitted written comments

"After ethical review – guidance for researchers"

Copy to: Mrs Sylvia Warwick, Berkshire Healthcare NHS Trust

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## Appendix 2 - Summary of literature findings

No.	Author(s)	Aim of Study/Paper	Methodology	Data	Context	Main Findings	Strengths	Weaknesses
1	Armour et al. (2009)	To examine the lived experiences of African Americans who are recovering from serious and persistent mental illness (SPMI).	Mixed-methods guided by hermeneutic phenomenological approach	Psychological measures and semi-structured interviews	USA	Social and professional relationships are important to the recovery process.	Sensitivity to context, commitment and rigour, sensitivity to culture.	No mention of ethics approval.
2	Borg and Davidson (2008)	To explore how persons with severe mental health problems experience recovery in the context of their everyday lives.	Qualitative narrative phenomenological approach	Semi-structured interviews	Norway	Recovery unfolds in the context of everyday life activities.	Sensitivity to context, commitment and rigour.	Poor choice of study methodology.

3	Bizub (2013)	To explore experiences of being prescribed medication during the acute phase of a mental health problem.	Qualitative narrative phenomenological approach	Retrospective account	USA	Side-effects of anti-psychotic medication are debilitating, disempowering and alienating.	Good sensitivity to context and rigour.	Procedures for obtaining ethical approval and informed consent not specified.
4	Brijnath (2015)	To apply CHIME to two culturally diverse groups.	Qualitative	Semi-structured interviews	Australia	CHIME was applicable in both cultures, but culture mediated sub-components of CHIME.	Sensitivity to context, sensitivity to culture, commitment and rigour.	Type of qualitative approach not stated.
5	Bussema and Bussema (2007)	To explore closely the specific role spirituality and religion play in recovery for people with mental health problems.	Quantitative	Survey	USA	Religion and spirituality are important for recovery.	Sensitivity to context, evidence of reflexivity, commitment and rigour.	Study participants not representative . Survey not ideal for addressing experiences. No mention of ethics approval.
6	Davidson	To focus on the	Qualitative	Semi-	USA	Participants	Commitment	Poor sensitivity

	et al. (2010)	wishes, the role of the mental health services, and the choices for the participants.		structured interviews		reported senses of loss and despair, and a sense of disorientation.	and rigour, transparency and coherency.	to context. Composition of the participants not specified.
7	Deegan (2005)	To understand how people, demonstrate the capacity for resilience in relation to psychiatric medication.	Qualitative	Semi-structured interviews	USA	Participants devoted more attention to personal and non-pharmaceutical medicine.	Sensitivity to context, commitment and rigour.	Composition of participants not specified.
8	Dein and Cook (2015)	To explore the experiences of communications from God.	Qualitative	Semi-structured interviews	Britain	Communications from God provide direction, comfort, agency and empowerment.	Sensitivity to context, commitment and rigour, clear research design.	The type of qualitative approach not specified. No mention of informed consent, confidentiality, potential participant selection bias. Composition of participants



								not specified.
9	Dein and Littlewood (2007)	To understand the different ways the congregation received God's voice.	Qualitative	Semi-structured interviews	Britain	God's voice can be received in different frequencies and diverse ways.	Demonstrates commitment and rigour in data analysis.	Research aims, recruitment of participants, methods of collecting data, ethics approval and informed consent not stated.
10	de Wet, Swartz, Chiliza (2015)	To find out experiences of recovery from first-episode psychosis in schizophrenia.	Qualitative	Semi-structured interviews	South Africa	Support and the need to care for another are important contributory factors for	Sensitivity to culture, commitment and rigour.	Aims of study not stated. Analysis not sufficiently interpretative.

						recovery.		
11	Edward et al. (2009)	To explore the meaning of resilience.	Qualitative	Semi-structured interviews	Australia	Showing greater resilience helps to overcome any life obstacles.	Sensitivity to context, sensitivity to culture, commitment and rigour, and transparency and coherence	Ethnic composition of participants not specified.
12	Gandi and Wai (2010)	To ascertain how partnership in coping impacts on mental health recovery.	Quantitative	Questionnaire	Nigeria	Partnership has a positive effect on recovery.	Sensitivity to context, sensitivity to culture, commitment and rigour, evidence of triangulation of data.	Views of participants not explicitly explored. Small sample for quantitative research. No mention of ethics approval.
13	Harrow, Jobe and Faull (2014)	To ascertain if multi-year treatment with antipsychotic medications	Quantitative	Prospective longitudinal follow-up	USA	A subgroup of service users not prescribed antipsychotic medication	Sensitivity to context, commitment and rigour,	Procedures for obtaining ethical approval not

		reduces or eliminates psychosis in schizophrenia.				experienced significantly less psychotic relapse over a long period of time.	transparency and coherence.	specified. Poor sensitivity to cultural context.
14	Hobbs and Baker (2012)	To identify sources of hope for recovery.	Qualitative grounded theory	Semi-structured interviews	Britain	Hope may exist in a variety of intensities and forms and this is often intermediated by social relationships.	Sensitivity to context, commitment and rigour, analysis grounded at the individual level.	Fails to reflect on the diversity of service users in England.
15	Kalathil (2011)	To explore unique stories of distress and recovery from mental health problems.	Qualitative	Semi-structured interviews	Britain	Recovery is intrinsically connected to the perceptions of the participants' mental distress.	Sensitivity to context, sensitivity to culture, commitment and rigour to the qualitative approach.	Participants not representative . Data analysis overlooked the heterogeneity and diversity of participants.
16	Kleintjes et al. (2013)	To report on the principal strategies of how nine national self-	Qualitative	Semi-structured interviews	International (multiple African countries)	Self-help organisations play a vital role in recovery for	Sensitivity to context, cultural sensitivity.	Does not specify the type of qualitative

		help organisations in seven African countries promote recovery.				service users in Africa.		approach used. Perspectives of service users not sought.
17	Kleintjes et al. (2012)	To document service users in South Africa's views on policy directions and service developments supporting recovery.	Qualitative phenomenological study	Semi-structured interviews	South Africa	Stigma, discrimination and disempowerment, and mental health related poverty were the dominating themes reported by the participants.	Sensitivity to context, cultural sensitivity, commitment and rigour to the qualitative approach.	Some core insights of the participants' narratives possibly lost in translation into English.
18	Leamy et al. (2011)	To undertake a systematic review of literature on personal recovery and to develop a new conceptual framework for recovery.	Systematic review and modified narrative synthesis	Published descriptions and models of personal recovery	International	13 features of the recovery journey and five processes of personal recovery (CHIME) emerged.	Sensitivity to context, sensitivity to culture, commitment and rigour, transparency.	Risk of replicating misleading outcomes of original studies.
19	Le	To identify	Systematic	Published	Britain	Three	Sensitivity to	Risk of

	Boutillier et al. (2015)	clinician and manager conceptualisations of recovery-orientated practice.	review and narrative synthesis	empirical studies		conceptualisations of recovery-orientated practice were identified: clinical recovery, personal recovery and service-defined recovery	context, commitment and rigour, transparency.	replicating misleading outcomes of original studies.
20	Le Boutillier et al. (2014)	To investigate the perceptions of staff support, barriers and facilitators of recovery-oriented service.	Qualitative grounded theory	Semi-structured interviews	Britain	Three conflicting sub-categories about how recovery-oriented is implemented emerged.	Sensitivity to context, commitment and rigour, transparency.	The ethnic composition of participants not specified.
21	Le Boutillier et al. (2011)	To identify the key characteristics of recovery-oriented practice guidance based on current international perspectives.	Qualitative analysis	International documents	Britain	Four practice domains of recovery emerged.	Sensitivity to context, sensitivity to culture, commitment and rigour, transparency.	Approach to identifying the study documents non-systematic. Documents for analysis not necessarily empirical

								research.
22	Mancini (2007)	To discuss the critical turning points instrumental in the recovery processes.	Qualitative grounded theory	Semi-structured interviews	USA	Transformation from illness, disability dominated identities, and identities dominated by agency and empowerment emerged as turning points of recovery.	Sensitivity to context, commitment and rigour, transparency and coherence.	Specific components of grounded theory not clearly specified or incorporated into the study. Study participants not representative .
23	McEvoy et al. (2012)	To understand the meaning of recovery from the perspectives of people with common mental health problems.	Mixed-methods quantitative and qualitative methods	Telephone interviews	Britain	Having a greater sense of balance and control to pursue personal goals were linked to recovery.	Sensitivity to context, commitment and rigour.	No discussion about ethics approval. Does not reflect on the multicultural diversity and perspectives of service users in Britain.
24	Pernice-Duca and Onaga	To gather information relating to social	Mixed-method cross-	Two separate interviews	USA	There is a strong link between social network	Sensitivity to context, commitment	19 percent attrition rate.

	(2009)	network and recovery processes of individuals participating in psychosocial clubhouses.	sectional, longitudinal design			and recovery.	and rigour, fair representation of ethnic minorities.	
25	Piat et al. (2009)	To understand the meaning of recovery for mental health service users.	Qualitative	Semi-structured interviews	Canada	Medical (clinical) and psychosocial emerged as conceptualisations of recovery.	Sensitivity to context, commitment and rigour, accountability.	Type of qualitative approach and composition of participants not specified.
26	Piat, Sabetti and Bloom (2009)	To report consumers' opinions on the role of medication.	Qualitative	Semi-structured interviews	Canada	Complex and multifaceted views about medication were expressed.	Sensitivity to context and cultural context, commitment and rigour, transparency and coherence.	Type of qualitative methodology not specified.
27	Sagan (2015)	To explore the meaning making of people with mental difficulties engaging in an	Qualitative IPA	Narrative interviews	Britain	Artistic activity and hope	Good sensitivity to context, rigour and commitment	Does not mention ethics approval and consent. The ethnic

		ongoing visual art practice.				provided a springboard for the participants' autobiographical analysis.	to IPA.	composition of participants not stated.
28	Schön, Denhov and Topor (2009)	To determine factors decisive to people's recovery.	Qualitative grounded theory study	Semi-structured interviews	Sweden	Social networks are pivotal to recovery.	Sensitivity to context, commitment and rigour, transparency.	Does not mention ethics approval for the study.
29	Sheridan et al. (2014)	To establish, implement and evaluate a supported friendship and socialisation programme for individuals experiencing persistent mental health problems.	Quantitative randomised controlled trial (RCT)	Controlled experiment	Ireland	Positive benefits of socialisation.	Uses RCT, the gold standard for research. Sensitivity to context, commitment and rigour.	Does not specify if it was a blind study. The ethnicity and racial composition of the participants not specified.
30	Slade et al.	To validate the	Systematic	Previously	International	Identified 115	Sensitivity to	Risk of



	(2012)	existing conceptual framework of recovery and country distribution.	review	published systematic review and narrative synthesis	l literature	papers describing 105 conceptualisations of recovery.	context, sensitivity to culture, commitment and rigour, transparency.	replicating misleading results. Not clear how linguistic and cultural differences were accounted for.
31	Tew et al. (2012)	To find out the effects of social factors on recovery.	Systematic review	Synthesis of literature	International literature	Relationships with significant others and other social factors have a significant positive effect on recovery.	Sensitivity to context, sensitivity to culture, commitment and rigour, transparency.	Risk of repeating misleading results. Risk of publication bias.
32	Waynor et al. (2012)	To assess the relationship between hope and symptoms.	Quantitative	Questionnaire	USA	Experiences of psychiatric symptoms can lead to decrease in hope.	Sensitivity to culture, commitment and rigour.	Poor sensitivity to context. Does not indicate if sample was randomly selected. No justification offered about the sample

								size.
33	Whitley (2011)	To find out the relationship between religion and recovery.	Qualitative ethnography	Focus group and participant observation	USA	Religious activities enhance recovery.	Sensitivity to context, evidence of research linked to practice.	Does not mention ethics approval for the study
34	Windell et al. (2012)	To determine participants' personal definitions of recovery.	Qualitative IPA methodology	Semi-structured interviews	Canada	Significant multidimensional experiences and conceptualisations of personal recovery.	Analysis grounded at the individual level.	Poor sensitivity to context, poor commitment and rigour.

### **Appendix 3: The Interview Schedule**

As you know I am interested in exploring how it has been for you having mental health problems. I'm going to ask you about 9 or 10 questions and it will take about 60 minutes. First I'd like to ask a bit about your background:

#### **1. Where is your country of origin?**

**Follow-up Questions:** When did you come to live in England? Did you experience mental health problems in your home country? Do you ever travel to your country? Could you describe what is like for you when you are there?

#### **2. Can you tell me how you first came into contact with the mental health services in England?**

**Prompts:** How did you first become unwell? What happened after you became unwell? **(Generate questions from terms the respondents use).**

**Follow-up Questions:** Have you received treatment in your country before? Could you describe the care you receive in your country? Could you tell me more about the traditional treatment in your country?

#### **3. How would you explain or describe the mental health problems you have?**

**Prompts:** Has anyone given you a diagnosis? What does that mean to you? Was it helpful? What is your understanding of...(the participants term). What does hearing voices mean to you? **(Or the terms the participants use).** When you say **(the participants term)** what do you mean by that? Could you tell me more about that?

#### **4. Are there any aspects of your way of life (culture, traditions and values) that have impacted on your experience of mental health problems?**

**Follow-up question:** Do you think that your cultural background has impacted on the services you receive at all?

**Prompts:** For you what does it mean to be an African with mental health issues (or terms the participants use) living in a foreign country? Can you tell me some of the issues you have faced because of who you are? What do you feel your background (culture, values, traditions, and

religion) is impacting on the services you receive in England? Tell me more about that.

**5. In what ways has your mental health problems affected you?**

**Prompts:** How has your mental health problems impacted on your life? Are there anything that have not been affected, that remain the same? Like what? Have there been any positive gains from your experience of mental health problems? Tell me more about that.

Has your mental health problems affected the way your (family or community) see you or behave towards you? How do they respond to you when you are not feeling well? And how do they respond to you when you are well? Has this affected the way you see your (family or community).

**6. What has helped you to cope with your mental health problems?**

**Prompts:** Do you have any support from other people to help you when you are unwell? Tell me more about that. Who gives you the support? (e.g. if mental health professionals and/or social networks) how did you meet them? What do they do for you? Which of these has been most important?

**7. Are there things that you think might have helped you that you did not receive?**

**Prompts:** Is there anything you think would have helped you cope with things better?

Do you feel you needed support from other people with similar issues like yourself? Do you think you needed a different treatment? Tell me more about that. Do you think you needed different services? Tell me more about how you think it would help you.

**8. How will you know when you no longer need the services?**

**Prompts:** How do you feel about your life now? Do you take any medication? Why do you take the medication? Has anyone told you how long you may need to be in contact with the mental health services? What is your aspiration in life? How do you see yourself in the coming months or years?

**9. Is there anything else that you think is important that we have not mentioned?**

## Appendix 4: Participant Information Sheet

**Title of Research Project:** Black African Service Users Experience of the Recovery Approach in Mental Health Provision in England. An Interpretative Phenomenological Analysis.

Dear \_\_\_\_\_,

You are invited to take part in a research study exploring the experiences of BASUs recovering from mental health problems-. Please read the following information to find out what this study is about before you decide whether to take part.

### Purpose of the Research

This research seeks to gain a better understanding of the experiences of BASUs recovering from mental health problems. As a researcher, I would like to gain a deeper understanding of the experiences of BASUs on the recovery oriented approach in mental health care system in England; and also, to find out how does a recovery orientated approach provide adequate cultural sensitivity in aiding BASUs mental health recovery.

**Name of Researcher:** This study is being carried out Isaac Tuffour a Community psychiatric nurse as part of his PhD study in Mental Health Nursing, at the Department of Mental Health and Learning Disability, City University, London. Isaac also works at Prospect Park Hospital with the Crisis Resolution and Home Treatment Team.

**Name of Research Supervisors:** The study is being supervised by Professor Sally Hardy, Dr Julia Jones, and Dr Alan Simpson at City University, Department of Mental Health and Learning Disability.

**Who is being recruited to take part in this study?** This study requires between 10-15 BASUs from various adult mental health services with Berkshire Healthcare NHS Foundation Trust. It is thought that BASUs with a diagnosed mental illness may be in a better position to help I to understand in detail the experience of recovery from mental health problems.

**What is involved in taking part?** This study involves you meeting with I for a face-to-face interview between 60 and 90 minutes. For privacy and confidentiality purposes, the interviews will take place in one of the consultation rooms of Berkshire Healthcare NHS Foundation Trust hospitals/facilities, or at a place where your privacy and confidentiality will be guaranteed. On the day of the interview, you will be given a consent form to sign and will

be also asked to complete a short questionnaire about yourself answering standard questions such as gender, age, country of origin etc. You will then be asked to participate in an individual interview of exploratory nature and will be expected to share your experiences of recovery from mental health problems with I. You may be invited to participate in a focus group discussion after the initial interview where your perceptions and opinions will be sought to verify I's themes from the interviews.

**Do I have to take part?** You have a voluntary decision of whether to participate in the research. It is important for you to know that although this study is being carried out with NHS patients, it is not related to your routine care nor it is part of an NHS-led research. So, your participation in this research project is entirely voluntary and will not affect your current or future care in the NHS. If you do decide to take part, you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part, you are still free to withdraw at any time and without providing an explanation.

**Will participation in the study be confidential?** All information you provide I with will be kept confidential and safeguarded at all times. Although your care team will be notified about your taking part in this study, they will not be given any information about what you shared with I during the interview. As part of the duty of care there are, however, a few exceptional circumstances in which your confidentiality cannot be kept. For example, if, during the interview, you share with your intention to self-harm or to harm others or information regarding any professional malpractice then it would be necessary to inform the relevant third parties. During the interview, only first names will be used in order to keep confidentiality. I will then change the names for anonymity. The interviews will be audio recorded. The interview tapes and questionnaires will be labeled by using research participant codes rather than actual names. All data about this study will be stored in a safe locked location which will only be accessible to I. The interview tapes will be transcribed and analysed by I.

**What are the possible risks of taking part in the study?** The subject matter of this study is sensitive and can be very emotive. You may find that talking about your experiences of mental health problems may remind you of difficult times and may cause discomfort and distress. If this happens for you, please remember that you can take a break or stop the interview at any time.

**What are the possible benefits of taking part in the study?** During your interview you will have an opportunity to speak openly and honestly about your experiences. Previous research suggests that talking about and reflecting upon difficult experiences and airing your views can be beneficial.

**What will happen to the results of the research study?** The results of this study will be used for I's final doctorate thesis at City University, London. They may or may not be used in academic/professional discussions and/or publication in professional journal or the equivalent. If the findings of this study get published in a research paper or get used in professional discussions I will change the names for anonymity. I will also prepare a short 'lay person's summary of research findings for general distribution when this study is concluded. If you are interested in having access to this summary please contact I whose

details are below.

**Who has reviewed the study?** This study was given a favourable ethical opinion for conduct by the Berkshire Research Ethics Committee. If you have any concerns about the way you have been approached or treated in the course of this research and you want to make formal a complaint please note that you can contact the local Patient Advice Liaison Service (PALS) to receive assistance. PALS are at Building 1, Room 1.1.13. Prospect Park Hospital, Honey End Lane, Reading, RG30 4EJ.

**Can I complain about the study if I don't like something about it?** If there is an aspect of the study which concerns you, you may make a complaint. There are two ways you can go about this:

- City University has established a complaints procedure via the Secretary to the Research Ethics Committee. To complain about the study, you need to phone **020 7040 3040**. You can then ask to speak to the Secretary of the Senate Research Ethics Committee and inform them that the name of the project is: **A Study of the Experiences of BASUs (BASUs) of Mental Health Provision in England**.

You could also write to the Secretary at:

- Anna Ramberg  
Secretary to Senate Research Ethics Committee  
CRIDO  
City University  
Northampton Square  
London  
EC1V 0HB  
Email: [Anna.Ramberg.1@city.ac.Britain](mailto:Anna.Ramberg.1@city.ac.Britain)
- The complaint procedure to the Berkshire Healthcare NHS Foundation is through the Trust's manager for Research & Development. To complain about the study, you need to contact:

Mrs Sylvia Warwick, Research & Development Manager, Berkshire Healthcare NHS Foundation, [REDACTED]

[REDACTED]

Email: [REDACTED]

Telephone: [REDACTED]

**What are the indemnity and compensation arrangements for this study?** This study is co-sponsored by City University and the Berkshire Healthcare NHS Foundation Trust. Arrangements for insurance and/or indemnity to meet any potential legal liability arising from harm to your participation in this research have been made by the sponsors.

#### **Contacts for further information:**

**1. Researcher:** Isaac Tuffour Tel: [REDACTED] Email: [REDACTED] Crisis

Resolution and Home Treatment Team, Prospect Park Hospital, Reading.

**2. Research Supervisors:** all at City University at the Department of Mental Health and Learning Disability. Tel: [REDACTED]

a. Professor Sally Hardy ([REDACTED])

b. Dr Julia Jones ([REDACTED])

c. Professor Alan Simpson ([REDACTED])



**Appendix 5: Participant Consent Form**

**Title of Research Project:** Black African Service Users Experience of the Recovery Approach in Mental Health Provision in England. An Interpretative Phenomenological Analysis

**Researcher:** Isaac Tuffour

**Please initial box**

- I confirm that I have read and understand the participant information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
- I understand that my participation is voluntary and that deciding whether or not to take part will not affect my current or future treatment and that even if I decide to volunteer I am free to withdraw at any time without giving any reason.
- I understand that relevant sections of my medical notes and data collected during the study may be looked at by individuals from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.
- I understand that the research interview will be audio recorded.
- I understand that my information will be kept securely and any information that I provide will be dealt with in a confidential manner.
- I understand that unidentifiable quotes from my interview may be used in publications and in professional discussions.
- I agree to take part in the above study.

.....

Initials

.....

Date

.....

Signature

## Appendix 6: Interview with Jane

Emerging themes	Original Transcript	Exploratory Comments
	Isaac: First of all I will like to know a bit about your background. Can you tell me where you come from originally?	Migrated from Sierra Leone
Migrant	Jane: I came from Sierra Leone; my origin is from Sierra Leone.	Jane describes that she was born and raised in Sierra Leone and migrated to England in the late 1990's
Refugee	Isaac: Were you born in Sierra Leone?	
War	Jane: Yeah	
Atrocity		
Trauma	Isaac: When did you come to live in England?	Displaced internally in her own country
Physical and psychological trauma	Jane: I came here in 1999	
Struggle for freedom	Isaac: Can you tell me how you came here?	Reason for migrating to England
Freedom	Jane: I came here because I was a refugee back home, we had a war. I struggled to come to England. It was difficult, so we had to fight for visas to come to the United Kingdom. So, I finally got my visa in Gambia to come to the United Kingdom	Refugee
Emancipation		'we had a war' –is interesting. Did she take part in the war? If so did she experience any physical and psychological trauma?
Internal displacement		
Victim of war	Isaac: So, did you come here alone or with family?	'so, we had to fight for visas' – this suggest difficult migration process, a struggle. Does this signify emancipation or freedom for her? Given that she was resettled in England
Trauma or war	Jane: I came here alone	
First contact with the MH services	Isaac: How did you come to live in (this town)?	
Trauma: pregnancy and childbirth	Jane: I came to live in (this town) ...because my mum was living here in ... I came through UNHCR	Victim of war She has experienced trauma of war
Descriptions of MH problems	Isaac: Can you tell me when you first became unwell?	First contact with the MH services- when she had her first child.
Self-harming and	Jane: I first became unwell when I	

suicidal thoughts	had my first baby. When I had Nick	Caesarean – does this suggest
Nostalgia	(not real name). When I had Nick	trauma for her?
Loneliness	the birth was caesarean. So, I went	
Safe-haven	into... That's when I started	
Not the right home	experiencing.... Since the	
Physical and emotional trauma	pregnancy, I started experiencing	
Lack of freedom	...I'm not feeling well, and my head	
First contact with the MH services	is not steady. I became unwell.	
Traumatic childbirth	Isaac: How long ago was this?	
Depression	Jane: That was... How old is Nick	
Post-natal depression	now?	
Not a mental health problem	Isaac: So, Nick is your first born?	Jane appears to make sense
Denial	Jane: Yeah, Nick is my first born.	that her difficult pregnancy
Depression	Isaac: How old is he?	and traumatic childbirth led
It is only a depression	Jane: He's 9 now	to experiencing MH problems
First contact with the MH services	Isaac: So roughly you first became	leading to her first contact
First admission	unwell about 9 years ago	with the services.
I am not mentally ill	Jane: Yeah	Nostalgia
	Isaac: So, what happened, you were	Was suicidal and missed her
	pregnant, you said, can you talk me	family back home.
	through what happened?	
	Jane: When I was pregnant, I had	Body was not in the 'right
	this experience, suicidal and	home'- what does she mean
	wanting to kill myself. Because I	by this?
	miss my family back home so I	Does 'right home' mean
	wanted to kill myself... my body was	Sierra Leone?
	not in the right home. My body was	She was fleeing war in Sierra
	very... rotating I wasn't feeling well.	Leone and was given a safe
	Isaac: Can you tell me if you were	haven in England but she still
	you unwell in Sierra Leone as well?	feels it is not the right home
	Jane: When I was in Sierra Leone, I	for her.
	was being disciplined by my dad and	<u>Is 'right home' always the</u>
	step-mother. Not I wasn't feeling	<u>country of birth for Black</u>
	well but I wasn't okay because I was	<u>Africans?</u>
	under control by them.	Disciplined by her dad and
		step-mother.
		'I was under control by the'.
		What sort of discipline?

	Isaac: So, you say under control by them, what do you mean by that?	Physical or emotional or both? What does she mean 'under control'?
	Jane: What I mean by under control, I mean I was under guidance. Monitoring, I was under monitoring.	The experience of being controlled in her native country is embedded in her memory.
	Isaac: Did you receive any treatment in Sierra Leone?	<u>Could such experiences be compared with being monitored on the ward?</u>
Lack of motivation	Jane: I didn't receive any treatment	Under guidance
	Isaac: So how did you first come in contact with the mental health services in England?	Has not receive treatment in Sierra Leone
	Jane: I came in contact when I had my first baby. I came in contact because when I had my first baby there was depression, so I was feeling depressed, I wasn't feeling well. They said it was depression until I came into mental health hospital. I wasn't taking part in activities or associating with friends like I used to. I didn't think it was a mental problem, I didn't think it was that because I was just lying down not having anything to do, not going to work. Because I was not going to work, I was not doing activities, working at Asda and now I was just lying down not doing anything and this was down to mental health problem. Obviously, I didn't think it was down to mental health problem I was thinking that was having depression because I was having my first baby.	First contact with the MH services
Anhedonia		She first came into contact with the services after a traumatic child birth
Lack of pleasure		Depressed and withdrawn, and not feeling well.
Informal admission		<u>Does it mean that she was experiencing post-natal depression?</u>
Family concerns		She did not think that her presentation was a MH problem. Why does she think like that? What is her view of a MH problem?
Challenges		She thought that it was only 'depression'. She does not think that depression is also a MH problem. Why?
Pain		Her first contact with the services led to her first admission.
Suffering		If she does not feel that she was mentally ill why was she
Guilt		
Burdensomeness	Isaac: So you think depression is not mental health?	
Bizarre experience	Jane: Depression. I don't know if depression is mental health.	
Strange things	Isaac: Were you admitted when you	
Confusion		
Focus on diagnosis		
Apathy		

Suggestible	first came in contact with the	admitted?
Disagreement of diagnosis	mental health services, or what happened?	She was not motivated to do things
I miss my family	Jane: I first came in contact with the mental health services in 2003. They	Anhedonia
Self-harming and suicidal thoughts	admitted me because I wasn't feeling well,	Not able to experience pleasure
Strong family support	Isaac: Do you know what happened, can you tell me more?	
Explanatory model of MH problem	Jane: I don't know what happened. I know that I was just lying down on my bed not doing anything, not	
Bereavement	doing any productive work. I was just lying down. That's what makes	Admitted as an informal patient.
Loneliness	them think it was a mental problem.	Was admitted for only two weeks. Relatively short admission.
Support network	Because I was lying down not taking part in activities. You know my body	
Support from own community	is not in the right shape or form. You know, my body isn't in the right state.	Strange experience of seeing doctors
Positive support from others	Isaac: So, you were admitted?	Disempowerment?
Solidarity	Jane: Yeah I was admitted	Family was concerned
Confusion	Isaac: Can you tell me, were you admitted to hospital as an informal patient or what happened?	Family support
Medication		Did she feel that she was a burden to her family?
Explanatory model of MH problems	Jane: I came into hospital as informal patient. Two weeks after that they discharged me.	Guilt, burdensomeness, ashamed?
It is different here		Shame
Stress	Isaac: What did you think was going on? What was it like going to the hospital for the first time?	Focus on diagnosis
Africa is different		
Explanatory model of MH	Jane: It was strange. It was strange. Because I see doctors going up and down up and down. Strange things.	She does not particularly remember all her diagnoses. What is going on with her?
Stressful living	I see the doctors going up and down with the instruments. Everybody	
Resistance	was concerned what was going on...	Has her experience of MH problems made her apathetic of how he is labelled?

Stigma		it was difficult	She disputes the diagnosis of schizophrenia and explains that missing her family and trying to kill herself does not mean that she has schizophrenia.
Discrimination		Isaac: And did you ask anybody what was going on?	
Injustice		Jane: I didn't ask, because I was in a state of shame	
Oppression			
Negative experience	social	Isaac: What happened, were you given any diagnosis?	
Lack of opportunities	of	Jane: They said it was depression. I've forgotten... the depression	
Lack of opportunities	of	Isaac: Schizophrenia?	
Unemployment		Jane: Yes, schizophrenia.	
Stigma		Isaac: Do you agree with this diagnosis?	Emotional support from family.
Discrimination		Jane: Not that I agree with diagnosis of schizophrenia, I know I nearly want to kill myself because I missed my family. I wouldn't put it down as if it is schizophrenia	
Injustice, oppression			Jane talks about her experience of how her dad came to visit her and she told him of her diagnosis. This seems to also convey a sense of strong family support.
Confusion			
Overwhelmed with MH problems		Isaac: So, what do you think it is then?	
Discrimination		Jane: It's depression. I think it's just depression	
Injustice		Isaac: So why did you want to kill yourself?	Jane talks about support from her family back home, she curiously uses 'back home' to mean her native Sierra Leone.
Oppression			
Shadow of former self		Jane: Because I was missing my family back home	She describes that her family are 'not worried because everything would be okay'. This conveys a strong emotional support from her family.
Explanatory model of MH problems		Isaac: Are you in contact with the family back home?	
		Jane: Yeah	
Personal and familial responsibilities		Isaac: what do they think about your illness?	This seems to mean a sense of strong family bonding.
Stress		Jane: They are not worried as such, they are not worried because	Jane talks about the death of

	everything will be okay	her mother-Bereavement
	Isaac: Have you told them what's going on with you?	Expresses bereavement.
	Jane: I told my dad. Because my dad visited me	She speaks about how she misses her late mother
	Isaac: Your dad visited you?	Explanatory model of MH problem
Resourcefulness in recovery	Jane: Yeah	Yeah it affected me because I miss her. I know someone like her. I miss her. In the community. I miss her a lot
Spirituality	Isaac: Apart from your dad, you said your mum lives here, are you still in contact with your mum?	Support network
Activities of daily living	Jane: My mum died	Support from the community
Shadow of former self	Isaac: Your mum died?	Her perception of what others think of her MH problems suggests that she gets positive support from others. She feels less stigmatized.
Stigma by family	Jane: Yeah	
Pejorative treatment by family	Isaac: I'm sorry to hear that. What does it mean to you?	
Sympathy by family	Jane: When she died?	
Shadow of former self	Isaac: Did it affect you? Your mental health?	Is she confused about what medication she is taking?
Stigma by family	Jane: Yeah it affected me because I miss her. I know someone like her. I miss her. In the community. I miss her a lot.	In what ways is medication helpful for her?
Sympathy by family		
Pejorative treatment by family	Isaac: Do you have any other family members here in England?	Things are done differently in England
Shadow of former self	Jane: I have friends. I have friends.	People think differently in England
	Isaac: Meaning friends from Sierra Leone or friends from where?	The way of life and thinking and living in England is stressful and it causes MH problems for Black Africans in England.
Medication	Jane: Friends from Sierra Leone	
	Isaac: What do they think about your mental health problems?	
Medication	Jane: I don't know what they think.	Africans think and do things differently, they also live more relaxed life and in good
Symptoms	They think it's okay, they think it's	

reduction	fine	atmosphere
Control	Isaac: So, Jane, are you on medication at the moment?	
Support by others	Jane: I don't know, it's helpful	Stressful living
	Isaac: You don't know much about medication? And do you find it helpful	Jane describes that living in England is stressful and has contributed to her mental health problems.
	Jane: Yeah, it's helpful.	
	Isaac: So what does it mean for you to be somebody coming from Sierra Leone and having mental health problems in England?	Negative social experience
	Jane: I don't know... maybe it's the way of doing things different. They way of thinking, the way of doing things, its different. That causes mental health problems because in this country you do it like this and like that and like this (hand gestures-stretches palm and turns up and down twice). In Africa, we don't have that. We have more of relaxation, more of good atmosphere. In here we have good atmosphere but people are more concentrated in work. It's stressful.	Discrimination due to her MH problems
Meaning of recovery		Lack of opportunities
Under control		Discrimination, injustice, oppression
Lack of self-determination, Lack of autonomy	Isaac: Is it stressful in this country for you?	<u>She describes how she has lost her personality</u>
Lack of privacy	Jane: Yeah	Changes in behaviour and physical appearance due to MH problems.
Lack of agency	Isaac: Do you think that living in this country has contributed for you becoming unwell?	People reacted to the changes in behaviour and appearance.
Focus on experience	Jane: Yeah it has because I had to work hard and I wasn't feeling well and I became unwell and depressed. Everywhere I go for job they say I have mental health	<u>Explanatory model of MH problems</u>
Confrontational attitudes		Increased in responsibility
Aggression		
Hostility		



Constant control	problems. They class you as that.	due to household responsibilities
Compromise	They say you aren't entitled to the job, but you aren't feeling well	
Acceptance of control	Isaac: So, you are not getting any jobs?	She was stressed with family responsibilities
Under control	Jane: Not getting any...	
Lack of self-determination, Lack of autonomy	Isaac: Do you think it is because of your mental health problems?	
Lack of privacy	Jane: ... I don't like people telling me I have mental problems	
Lack of agency	Isaac: So, what do they tell you when you go for a job?	
Isolation		
Loneliness	Jane: 'You are not allowed to get a job'	Spirituality (my praying will never change)
Isolation		
Loneliness	Isaac: Why do you think they say like that?	
Fighting against stigma, gossip and negative stereotypes	Jane: I don't know	
Stigma	Isaac: So apart from this, what are some of the difficulties you face because of who you are and your mental health problems?	
Isolation	Jane: I don't know... I don't know...	Focus on self. Shadow of former self
Judgemental attitudes by others	Isaac: So, can you describe yourself before you were diagnosed with schizophrenia and depression?	<u>I will not party anymore</u>
Hypocrisy of others	Jane: Well, I was well. I was fit. I was size 8. Going out, going clubbing, going shopping, going raving. I was doing all these things. But when I first became weak, I was not doing all these things. That's why people were concerned and saying that I was depressed because I'm the one that goes out, doing things, having fun, raving, and doing all these things because I'm not doing things,	My family will not see me in the same way Does she think her family discriminate against her? Will they treat her in pejorative manner? What does it mean by this? Shadow of former self
Medication		
Recovery		

all the community get shocked because I'm not going out, I'm not having fun so people are getting worried, 'why isn't this bubbly girl not having fun? She used to have fun; she used to get down on the floor. Why is she not having fun now?' And so people worry, that's why I'm in here.

Isaac: So, what do you think was going on?

Changes in physical appearance

Jane: It's because I had my first baby, that's why everything stopped. Because when you have your first baby, everything stops because you have more responsibility, you have more responsibility to work on boyfriend, to work on kids, family tasks, to work on all these tasks. The responsibility becomes more once you have your kids. Once I wasn't having kids, I was different. When I didn't have my kids it was completely different story because there was no responsibility and I want to go down like this.

Views on medication

Jane describes how medication has helped to alleviate her symptoms however, she feels that being told to take medication for a long time is 'monitoring', in other words a form of control

Isaac: So, for you Jane, what are some of the areas in your life that have remained the same or remained unaffected by your mental health problems?

Jane: There are things that will never change. Things like my praying will never change, my hobbies will not change. Things like that will not change

Support

Isaac: So you are still able to clean, able to enjoy your hobbies and able to do other things that you enjoy

Jane describes that having household assistance and assistance with medication though she initially states that

doing?

she does not have 'much support'.

Jane: Yeah

Isaac: What are some of the things in your life that have been affected because of your diagnosis?

What or how much support does she need for it to be enough for her?

Jane: Family. My family... the way I used to party, I will not party anymore. The way I used to complete tasks, I will be able to fulfil tasks.

Isaac: So how has your diagnosis affected you and your family?

Jane: My family will not see me in the same way

Isaac: They will not see you in the same way?

Jane: Yeah

Meaning of recovery

Isaac: In what ways?

Jane: At first I wasn't mentally disturbed, now I am mentally disturbed they will not see me the same way. The way I have changed. The way I talk has changed. They will not see me in the same way. Everything has changed.

Jane uses 'monitoring' as a powerful sentiment of constantly being under control. She feels that she lacks self-determination, autonomy, and privacy. There is no agency in her experience.

Isaac: So, your body has changed, the way you talk has changed, your family's attitude towards has changed?

She makes this statement to depict how she would feel that she is recovering:

Jane: Yeah

Isaac: Why do you think you talk in the way you talk?

If I'm healthy, if I'm going out, dancing without no monitoring.

Jane: I don't know. I never used to talk like that. I used to talk very clearly. My face is puffier. My face

Focus on experience

never used to be like this

Isaac: What do you think is happening?

Jane: I don't know

Isaac: So, Jane let's talk a bit about your medication. What do you think about medication?

Jane: It's helped me a lot. Because I used to have pains in my head and pains in my body and now it's gone.

Isaac: So, because of the medication you don't experience any pains?

Jane: No

Isaac: How does it mean for you to be told that you must probably take medication for a long period?

Jane: Its monitoring

Isaac: Sorry?

Jane: It's monitoring. It's okay.

Isaac: So, you don't have any problems with monitoring?

Jane: No

Isaac: What is some of the support that is available for you?

Jane: I don't have much support. I have somebody who comes to my house every day. She helps me with laundry and things like that.

Isaac: And what else?

Jane: She helps with medication

Isaac: So, somebody comes in with every day with your medication?

Jane feels that she is under constant control, though she hints that she wouldn't mind a minimal control to help her with her recovery.

She feels that people attitude toward her is confrontational

This suggests a compromise in her narration.

Jane feels that she lacks self-determination, autonomy, and privacy because of her MH problems.

She feels shunned by people from her own community. This suggests that she is isolated from her own community because of her MH problems.

Isolation, loneliness,

Stigma

Jane: Yeah

Isaac: What else? What are some of the things that you feel you needed to help which you have not received now?

Jane: Nothing

Nothing? You can't think of anything?

Jane: No

Isaac: So, Jane how will you know that you will no longer need the services?

Jane: If I'm healthy, if I'm going out, dancing without no monitoring. Then I will be healthy.

Isaac: What does it mean to you to be healthy?

Jane: Healthy means doing things without monitoring. Doing your daily care. I have to go to the bathroom with no monitoring. I have to do my daily tasks with no monitoring. Doing everything without any monitoring without any help.

Isaac: Do you feel that being monitored all the time is a bit encroaching on your privacy?

Jane: Yeah, It's unhealthy

Isaac: It's unhealthy to you?

Jane; Yeah

Isaac: And what does it mean to you being monitored all the time?

Jane: It means that you are under

Bull shit suggests

Jane feels that the attitude towards her by her community members is nonsense, senseless.

Jane talks about her experience in a frantic way suggesting her determination to fight any stigma, gossip and negative stereotypes associated to her MH problems.

She feels isolated from her own community

Judgemental attitudes from her own community

Gossip and negative stereotypes

Hypocrisy or pretence of others attitude towards her.

control. You are under their control

Isaac: You don't want to be under control?

Jane: I want to be but not too much. I want to be under control, only two controllers. one giving my medication and one helping me with my daily tasks.

Isaac: So, you feel that now for you, you are being controlled here?

Jane: I'm under control because I'm not feeling well.

Isaac: What do you feel about other people's attitudes towards you?

Jane: People's attitudes are like they are looking for problem.

Isaac: What kind of problems are they looking for?

Jane: Fight (laughs)

Isaac: So, what about the attitude of people from Sierra Leone? Have they changed because of your mental illness?

Jane: I don't have people calling me. Yes they have changed

Isaac: You don't have people calling you?

Jane: They don't call me anymore. Mr Pee used to call me all the time

Isaac: You feel as if their attitudes have changed because of your mental illness?

Jane: Yeah

Isaac: Why? Why do you think like

that?

Jane: They don't call me anymore

Isaac: So, do you feel stigmatized because of your mental illness?

Jane: Yeah

Isaac: Can you tell me more about that?

Jane: I've been isolated. People that used to call me don't call me anymore.

Isaac: So, you feel you've been isolated.

Jane: Yeah. They're all hypocrites. They gossip 'You have mental health problems'. And that's a bad tag on my name.

Isaac: And what does that mean to you?

Jane: It means bullshit.

Isaac: Thank you for sharing your experience with me.

Jane: That's alright.

## Chronological List of Themes-Interview with Jane

Immigrant	Strange things	Stress
Refugee	Confusion	Resourcefulness in recovery
War	Focus on diagnosis	Spirituality
Atrocity	Apathy	Activities of daily living
Trauma	Suggestible	Shadow of former self
Physical and psychological trauma	Disagreement of diagnosis	Stigma by family
Struggle for freedom	I miss my family	Pejorative treatment by family
Freedom	Self-harming and suicidal thoughts	Sympathy by family
Emancipation	Strong family support	Shadow of former self
Internal displacement	Explanatory model of MH problem	Stigma by family
Victim of war	Bereavement	Sympathy by family
Trauma or war	Loneliness	Pejorative treatment by family
First contact with the MH services	Support network	Shadow of former self
Trauma: pregnancy and childbirth	Support from own community	Medication
Descriptions of MH problems	Positive support from others	Medication
Self-harming and suicidal	Solidarity	Symptoms reduction
	Confusion	Control
		Support by others
		Under control
		Lack of self-determination,
		Lack of autonomy
		Lack of privacy
		Lack of agency Isolation
		Loneliness
		Isolation
		Loneliness
		Fighting against stigma, gossip and negative stereotypes
		Stigma
		Isolation
		Judgemental attitudes by others
		Hypocrisy of others



thoughts	Medication
Nostalgia	Explanatory model of MH
Loneliness	problems
Safe haven	It is different here
Not the right home	Stress
Physical and emotional trauma	Africa is different
Lack of freedom	Explanatory model of MH
First contact with the MH services	Stressful living
Traumatic childbirth	Resistance
Depression	Stigma
Post-natal depression	Discrimination
Not a mental health problem	Injustice
Denial	Oppression
Depression	Negative social experience
It is only a depression	Lack of opportunities
First contact with the MH services	Lack of opportunities
First admission	Unemployment
I am not mentally ill	Stigma
Lack of motivation	Discrimination
	Injustice, oppression
	Confusion
	Overwhelmed with MH

Anhedonia	problems
Lack of pleasure	Discrimination
Informal admission	Injustice
Family concerns	Oppression
Challenges	Shadow of former self
Pain	Explanatory model of MH
Suffering	problems
Guilt	Personal and familial
Burdensomeness	responsibilities
Bizarre experience	

## **Appendix 7: Article submitted and accepted for publication by Mental Health Practice**

**Title:** The challenges of conceptualizing recovery

**Abstract:** Recovery is a contested concept scattered in various contexts and disciplines and thus, contributes to the confusion surrounding the concept. This article explores the various conceptualizations of recovery. A proposition for a pragmatic approach of viewing recovery as distribution across a continuum of clinical, social, and personal domains is made. The need for recovery to be conceptualized from the perspectives of other cultures is also suggested.

**Keywords:** Recovery, personal recovery, clinical recovery, social recovery

### **Introduction**

One of the main challenges facing service users, professionals, researchers and policy makers is the wide-ranging ways in which recovery is understood and conceptualized. Attempting to identify a concise definition of the concept is not a simple task. The scholarly literature is scattered with conceptualizations dotted in disciplines such as physical disability, addiction services, intellectual disability services, and the various specialities of mental health services. Furthermore, among the many contexts and disciplines that the term recovery is used are archaeology, conflict and policymaking, economics, arts and culture, sport, and even in transport, as in recovery vehicles (McCauley et al., 2015). These further complicate and muddy the waters for understanding the concept. The aim of this article is to explore some of the multifaceted ways in which recovery has been conceptualized in the literature.

### **The complexities of recovery**

The mental health recovery literature suggests that the concept is difficult to conceptualize (Lieberman and Kopelowicz, 2005; Onken et al., 2007; Roe, Rudnick and Gill, 2007). There is a consensus that recovery has different meanings to different stakeholders (Kelly and Gamble, 2005; McCauley et al., 2015). Discussions of recovery involve many terms, such as 'an approach, a model, a philosophy, a paradigm, a movement, a vision and, sceptically a myth' (Robert and Wolfson, 2004, p.38), a 'buzz word' or 'fad' (Piat and Lal 2012, p.294). It has thus, been criticised as an elusive and abstract concept (Davidson et al, 2005; Onken et al, 2007). This means that attempts to conceptualize a succinct construct of recovery are doomed if they fail to recognize that it is a contested construct.

McCauley et al. (2015) have highlighted many surrogate terms used in place of recovery by some influential individuals and many disciplines. For example, it has been conceptualized as 'the birth of hope' and 'resurrection' (Deegan, 1988, p. 56-57); and 'a journey of the human heart' (Deegan, 1995, p.92). Likewise, the medical meaning has influenced the conceptualization of recovery in the psychiatric and mental health nursing, and the behavioural sciences literature. Consequently, the terms 'recovery' and 'rehabilitation' are often used as substitutes (McCauley et al., 2015). Critics point out that the baffling use of interchangeable terminologies rooted in different philosophies are rarely made explicit (Collier, 2010; Davidson et al. 2005). It appears that attempts to conceptualize this complex and multifaceted concept have resulted in a terminological minefield. Reading through the extensive literature, one may be persuaded that perhaps a complete and succinct

conceptualization of recovery will always remain elusive. The literature does not offer an absolute definition. Instead, there are descriptions of quintessential qualities of recovery. There seems to be little, if any agreement on what constitutes a pure definition of recovery. Despite this, it is possible to identify many of the broad-spectrum definitions characterizing the concept.

### **Scientific and consumer-oriented definitions of recovery**

To begin with, some accounts illuminate dual conceptualization: scientific and consumer-oriented definitions (Bellack, 2006; Davidson and Roe, 2007; Slade, 2009; Silverstein and Bellack, 2008). Collier (2010, p.17) calls these the traditional and the contemporary definitions of recovery, or the 'medical' recovery and 'life' recovery. Others conceptualize recovery as either an outcome with operationally defined criteria, or as an on-going process encompassing self-concept (Silverstein and Bellack, 2008). Some of these conceptualizations are further discussed next.

#### **Scientific definition of recovery**

Broadly speaking, the literature considers scientific definitions of recovery from the perspective of disease and elimination or reduction of symptoms, return to premorbid state of function, use of medication, risk-management, and acquisition of activities of daily living (Le Boutillier et al., 2015). The scientific definitions are known to have derived from the historical context of clinical research (Bellack, 2006; Davidson and Roe, 2007; Slade, 2009; Silverstein and Bellack, 2008). Thus, it is also referred to as clinical recovery (Slade, 2009). Adeponle, Whitley, and Kirmayer (2012) observed that one appeal of scientific definitions lies in their claim to offer a consistent measure of outcome irrespective of individuals' cultural backgrounds and geographical settings. However, a more fundamental objection to this argument is that significant variations exist in different cultural systems about health and healing practices (Kirmayer, 2004). It is at least arguable that mental illness and recovery may manifest differently to a native British service user than for example a black African service user in Britain. In this sense recovery, cannot be defined by only scientific conceptualizations.

#### **Operational scientific definitions of recovery**

Some operational scientific definitions of recovery include that of Torgalsbøen and Rund (2002) who used the following criteria: 'a reliable diagnosis of schizophrenia at an earlier time but not at present; no psychiatric hospitalizations for at least five years; and present psychosocial functioning within the 'normal' range on the Global Assessment of Functioning scale' (p.312). An alternative operational definition is provided by Harrow, Grossman, Jobe, and Herbener, (2005) who developed an explanation requiring a year's period of absence of psychotic and negative symptoms; adequate psychosocial functioning including paid work half-time or more and the absence of a very poor social activity level; and no rehospitalisation. Yet another good example of scientific definition of recovery is provided by Liberman et al. (2002) who operationalized the concept with dual criteria of psychopathology and psychosocial functioning. The psychopathology criteria see recovery as symptom remission and scores '4' or less (suggesting moderate or less severity scores) on the Brief Psychiatric Rating Scale (Ventura et al., 1993). But the psychosocial functioning consists of vocational functioning with benchmarks such as full or parttime employment/education, involvement in recreational, family and volunteer activities; independent living without every day supervision by family or care providers; and relationships with significant others for regular social and

recreational activities (Liberman et al., 2002). Finally, Liberman et al. (2002) conclude that each of the above criteria must be sustained for at least two consecutive years in order to satisfy the standards for recovery.

The definitions above highlight that recovery is not only about symptom remission, but is also marked by a multiplicity of important life activities including work and social relationships. However, a notable limitation of these definitions is that they fail to address the subjective interpretation of the individual's level of functioning or the extent of the person's satisfaction with life (Bellack, 2006). Specifically, they fail to incorporate phenomenological and subjective experiences of the individuals experiencing mental illness. Moreover, as Bellack (2006) has pointed out, scientific definitions have been determined by consensus and not empirically. Accordingly, there is no gold standard to define certain criteria such as quality of life or service user satisfaction (Silverstein and Bellack, 2008). Likewise, prominent service-user issues such as the duration of recovery, acceptable residual symptom levels, as well as the acceptable functioning levels have not been analysed to ascertain construct validity. Bellack, (2006) also points out that the diverse perspectives of professionals, family members and consumers have not been systematically incorporated into the definitions. Finally, these conceptualizations must be interpreted with caution considering that definitions were reflections of the narrow confines of schizophrenia. The key points to note is that these definitions are not inclusive considering that a wider spectrum of diagnoses was not considered in these conceptualizations.

### **The consumer-oriented definitions**

The consumer-oriented definitions are also conceptualized as personal recovery. They view recovery as a non-linear process in which persons with mental illness strive to overcome their difficulties over time. These definitions evolved from the service user movements along with change in attitude about mental illness that was triggered by a combination of social and political factors. Essentially, the target audience for the consumer oriented definitions are service users, family members, politicians, policymakers, and clinicians. It has been argued that the overarching aims of these definitions are to influence policies and service provisions, as well as to overcome the negative consequences such as poverty, stigma, demoralisation, hopelessness and social isolation that are associated with mental illness (Bellack, 2006; Davidson and Roe, 2007; Slade, 2009; Silverstein and Bellack, 2008). Arguably, recovery in this context is conceptualized from the perspectives of reclamation of personal identity, dignity, and social inclusion.

There is plethora of consumer-oriented definitions of recovery causing further confusion and difficulty about the concept. But one of the early definitions and perhaps the most widely accepted process-oriented definition of recovery is by Anthony (1993):

*'A deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills, and/or roles. It is a way of living a satisfying, hopeful, and contributing life even with limitations caused by the illness. Recovery involves the development of new meaning and purpose in one's life as one grows beyond the catastrophic effects of mental illness' (p. 15).*

Another good example of a process-oriented definition is by Davidson et al. (2005):

*'A redefinition of one's illness as only one aspect of a multidimensional sense of self capable of identifying, choosing, and pursuing, personally meaningful goals and aspirations despite continuing to suffer the effects and side-effects of mental illness' (p. 15).*

The definitions above appear to put emphasis on empowerment, control, choices and self-determination as having a profound positive effect on the individual with mental health problems (Andresen, Oades, and Caputi, 2003; Slade, Amering, and Oades, 2008; Spaniol et al., 2002). Besides, they also seemingly appear to reject the scientific definitions of recovery (Andersen et al, 2003). But what is surprising is that Anthony (1993) was inadvertently associating personal recovery with scientific definition in his original construct when he suggested that service providers' vision of recovery from mental illness corresponds to 'cure or remission of symptoms'.

(Adeponle et al., 2012). This may not be surprising considering that some studies conclude that scientific or clinical definitions may exist in the minds of some service users (Davidson and Roe, 2007; Piat et al., 2009). Perhaps, it is also not an exaggeration to suggest that these two definitions complement each other. As Silverstein and Bellack (2008) optimistically argue, neither of the opposing definitions is exclusively unique. The authors also make the analogy about recovery that construct validity is not merely attained by using the most reliable research measures, but they are attained by first addressing the meaningful dimensions of recovery before identifying and developing how to assess these dimensions. Even with this optimistic perspective, it appears that there are numerous contradictions and complexities surrounding the conceptualizations of personal and scientific recovery.

### **Processes of personal recovery**

Some of the processes of consumer-oriented definitions include connectedness, hope and optimism about the future, identity, meaning in life, and empowerment, given the acronym CHIME, by Leamy et al. (2011). Along with this comprehensive description, recovery has also been perceived in the context of self-determination, agency, awareness and potentiality and taking responsibility (Andresen et al., 2003; Onken et al., 2007; Resnick et al., 2004). These processes of recovery are not exhaustive by any means, but they are cohesive in their service user centeredness, focus on individuality, self-control and quality of life.

Moreover, Silverstein and Bellack (2008) note that widely cited consumer-oriented definitions of recovery are characteristically generated by service users who have become experts by experience thus; their status within the professional community has propelled them into becoming mental health professionals. But, it remains unclear if the experiences of this cohort of experts are similar to the broader population of service users (Silverstein and Bellack, 2008). However, this criticism of consumer-oriented definitions may be a little harsh. Especially, considering that the contemporary notion of recovery is usually traced to the insights and writings of the personal and transformative experiences of individual service users like Lovejoy (1984); Chamberlin (1997); Deegan (1988; 1996); Leete (1989); and Unzicker (1989) who have articulated about their experiences of coping with symptoms, getting their strength back, and regaining a satisfactory sense of personal identity that was not defined by illness experience.

### **Criticisms of personal recovery**

Despite their powerful focus on service users, Bellack (2006) argues that some of the consumer-oriented definitions are relatively nonspecific, inadequate for research, ineffective for evaluation of clinical programmes or to develop public policy.

### **Recovery as an on-going social process**

A new view of recovery has emerged proposing that some aspects of recovery unfold within a social and interpersonal context and therefore recovery cannot be solely focused as deeply personal and unique individual process. For example, it has been noted that having one or more personal relationships as a source of hope and encouragement can be a critical factor in achieving recovery (Spaniol et al., 2002). Mezzina et al. (2006) has produced a framework depicting personal, interpersonal, and social domains, as well as the role of material resources and a sense of belonging as important sources of recovery. In this framework, the authors suggest the imperativeness of social inclusion, citizenship, and participation of community activities as vital source of recovery. Furthermore, a study by Topor et al. (2011) found that social relationships did not only play a central role in the recovery process, they helped individuals to feel that they are special. However, it has been suggested that the antagonistic experiences of disempowerment, injustice, abuse and resignation (Gilbert and Allen, 1998; Tew, 2011) play adverse effect on social relationships.

### **Recovery as a dimensional approach**

Evidence also suggests that recovery can be conceptualized in a multi-dimensional approach. A definition of dimensional approach of recovery emerged from a systematic review and narrative synthesis of staff understanding of recovery orientated mental health practice by Le Boutillier et al. (2015):

*'a holistic approach (spanning physical health care, psychological therapies and stress management) where individuality (including client-centred goals, service-user autonomy and decision-making) takes precedence, and staff and service users work in partnership (through, for example, coaching, supporting hope). Personal recovery was measured by citizenship involvement (including meaningful occupation and social inclusion)' (p.6).*

The definition above is comprehensive and covers aspects of clinical, physical, personal, social, and existential recovery. Furthermore, Whitley and Drake (2010) have proposed a compelling proposition that recovery can be conceptualized in five superordinate dimensions: clinical, existential, functional, social, and physical. Similar to the scientific definitions described above, the authors suggest that the clinical recovery involves reduction and control of symptoms. They also support this view by explaining that this form of recovery is often intermediated by psychotropic medication, psychological interventions, and often spearheaded by the clinical team. In this sense, the service users appear to lack control of their own recovery. Furthermore, Whitley and Drake (2010) elucidate that the existential recovery may incorporate many components such as religion and spirituality, agency and self-efficacy, empowerment that often allow the individuals with mental health problems to feel that they are in control of their own lives. The authors note that mental health services that take account of these existential needs of its service users are more likely to be effective. Interestingly, this form of conceptualization appears to be consistent with some of the processes of personal recovery discussed above. Functional recovery, according to the authors includes factors such as employment, education, and housing. Or in other words,

functional recovery is the ability of the person with mental illness to fruitfully participate in all aspects of everyday human experiences. In this sense, functional recovery appears to have similar characteristics to that of consumer-oriented definitions of recovery, as it appears to put more emphasis on psychosocial functioning of the person with mental illness. According to Whitley and Drake (2010), people with serious mental illness may also experience multiplicity of comorbid physical health problems. Therefore, for these people, physical recovery is about continuous improvements in physical health and well-being. This form of recovery also appears to identify more with clinical recovery due to its emphasis on elimination or reduction of symptoms. Finally, Whitley and Drake (2010) explicate that social recovery involves establishing and maintaining meaningful relationships with family, friends, peers, clinicians and significant others, and also engaging in social activities, and being integrated into the community. In this case, this form of recovery appears to be consistent with the social process of recovery discussed above, as it has been shown that some aspects of recovery unfold within a social and interpersonal context.

As we have seen, the dimensional approach to conceptualization of recovery provides a persuasive integrative approach of defining the concept. It appears to bring together the scientific-oriented definitions, consumer-oriented definitions, and the social processes of recovery under one umbrella. It appears that at the centre of the dimensional approach to conceptualizing recovery is consensus building; and in the final analysis the power ought to be given to the service users to decide which of these dimensions are applicable to them.

### **Conclusion**

Insights from the literature demonstrate that recovery is profoundly a contested concept that cuts across disciplines. It is therefore hardly surprising that such an important concept lacks a clear and concise definition. Perhaps, an absolute definition of recovery will always remain elusive. However, a pragmatic approach is to view the concept as distribution across a continuum of clinical, social, and personal domains. But one of the limitations with the conceptualizations is that they are dominated by the Euro-American perspectives and justifiably raise questions about the multi-ethnic relevance of the concept (Adeponle et al., 2012). Perhaps, conceptualizing recovery from the perspectives of other cultures would serve as a framework for the exploration of the concept in minority cultures.

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## Appendix 8: E-mail/letter of acceptance of article publication from the editor of journal

**Date:** 12 Jan 2017  
**To:** 'Isaac Tuffour' [REDACTED]  
**From:** 'Mental Health Practice (no reply)' noreply@rcni.com  
**Subject:** MHP1231 - Your submission has been accepted  
The challenges of conceptualizing recovery  
Mental Health Practice

Dear Mr Tuffour,

Thank you for your article, which I am pleased to accept for a future edition of Mental Health Practice.

It was accepted on 12 Jan 2017

Please note that in common with all professional publications your article will undergo editorial changes before going to print, which may include text changes, as well as changes to headlines and summaries.

We will send you a copy of the magazine in which your article is published and would be pleased to consider any further articles you feel might be suitable for publication.

Mental Health Practice offers authors the option to pre-pay to make the final version of their article freely available on publication through our Open Choice model. Details here: <http://rcnpublishing.com/page/authors/open-access-frequently-asked-questions>

If you would like your article published under Open Choice please email the administration manager: [REDACTED]

Yours sincerely,

Colin Parish  
Editor  
[REDACTED]

## Appendix 9 - Results of database search in CINAHL

#	Database	Search term	Results
1	CINAHL	('interpretative phenomenological analysis' OR 'IPA').ti,ab	921
2	CINAHL	('mental health' OR 'mental disorder*' OR 'mental illness*' OR 'mental disease*' OR 'mental problem*' OR 'mental health problem*').ti,ab	57650
3	CINAHL	('recovery*' OR 'recover*' OR 'recovering' OR 'rehabilitation*' OR 'survival*').ti,ab	133653
4	CINAHL	(African OR Black African OR Sub-Saharan African*).ti,ab	22087
5	CINAHL	(1 AND 2 AND 3 AND 4)	0
6	CINAHL	(1 AND 3)	97
7	CINAHL	(2 AND 6)	11
8	CINAHL	((('minority*' OR 'ethnic*' OR 'ethnic minority*' OR 'BME' OR 'BME groups' OR 'black) AND minority ethnic groups').ti,ab	307
9	CINAHL	(2 AND 8)	26
10	CINAHL	('Afro-Caribbean' OR 'African-Caribbean' OR 'Caribbean').ti,ab	1713
11	CINAHL	(2 AND 3 AND 10)	4
12	CINAHL	(hope*).ti,ab	16157
13	CINAHL	(2 AND 3 AND 12)	202
14	CINAHL	(healing*).ti,ab	21370
15	CINAHL	(2 AND 3 AND 14)	49
16	CINAHL	(spirituality*).ti,ab	4254
17	CINAHL	(2 AND 3 AND 16)	52
18	CINAHL	(empowerment).ti,ab	5443

19	CINAHL	(2 AND 3 AND 18)	136
20	CINAHL	(connection OR social network* OR support* OR social support).ti,ab	201308
21	CINAHL	(2 AND 3 AND 20)	1402
22	CINAHL	(self-control OR control*).ti,ab	261335
23	CINAHL	(2 AND 3 AND 22)	541
24	CINAHL	(8 AND 23)	0
25	CINAHL	(medication*).ti,ab	54897
26	CINAHL	(2 AND 3 AND 25)	198
27	CINAHL	(resilience*).ti,ab	3426
28	CINAHL	(2 AND 3 AND 27)	55
29	CINAHL	(systematic review OR meta-analyses OR quantitative).ti,ab	65667
30	CINAHL	(2 AND 3 AND 29)	145

## Appendix 10 - Results of database search in BNI

#	Database	Search term	Results
1	BNI	('mental health' OR 'mental disorder*' OR 'mental illness*' OR 'mental disease*' OR 'mental problem*' OR 'mental health problem*').ti,ab	15949
2	BNI	(IPA OR interpretative phenomenological analysis).ti,ab	204
3	BNI	(1 AND 2)	32
4	BNI	(recovery).ti,ab	2900
5	BNI	(1 AND 4)	764
6	BNI	(3 AND 5)	6
7	BNI	(systematic review OR meta-analyses OR quantitative).ti,ab	9144
8	BNI	(1 AND 4 AND 7)	29
9	BNI	((minority* OR 'ethnic*' OR 'ethnic minority*' OR 'BME' OR 'BME groups' OR 'black') AND minority ethnic groups').ti,ab	400
10	BNI	(1 AND 4 AND 9)	2
11	BNI	('Afro-Caribbean' OR 'African-Caribbean' OR 'Caribbean').ti,ab	244
12	BNI	(1 AND 11)	54

13	BNI	(2 AND 11)	1
14	BNI	(African OR Black African OR Sub-Saharan Africa*).ti,ab	2081
15	BNI	(1 AND 4 AND 14)	4
16	BNI	(1 AND 2 AND 14)	0
17	BNI	(hope*).ti,ab	1712
18	BNI	(4 AND 17)	131
19	BNI	(1 AND 18)	65
20	BNI	(healing*).ti,ab	2546
21	BNI	(4 AND 20)	69
22	BNI	(spirituality*).ti,ab	842
23	BNI	(4 AND 22)	16
24	BNI	(empowerment).ti,ab	1479
25	BNI	(4 AND 24)	47
26	BNI	(connection).ti,ab	610
27	BNI	(4 AND 26)	15
28	BNI	(support*).ti,ab	33558
29	BNI	(4 AND 28)	768
30	BNI	(1 AND 29)	266
31	BNI	(control*).ti,ab	18861
32	BNI	(4 AND 31)	322
33	BNI	(1 AND 32)	51
34	BNI	(medication*).ti,ab	6896
35	BNI	(4 AND 34)	101
36	BNI	(1 AND 35)	30



37	BNI	(resilience*).ti,ab	715
38	BNI	(4 AND 37)	30